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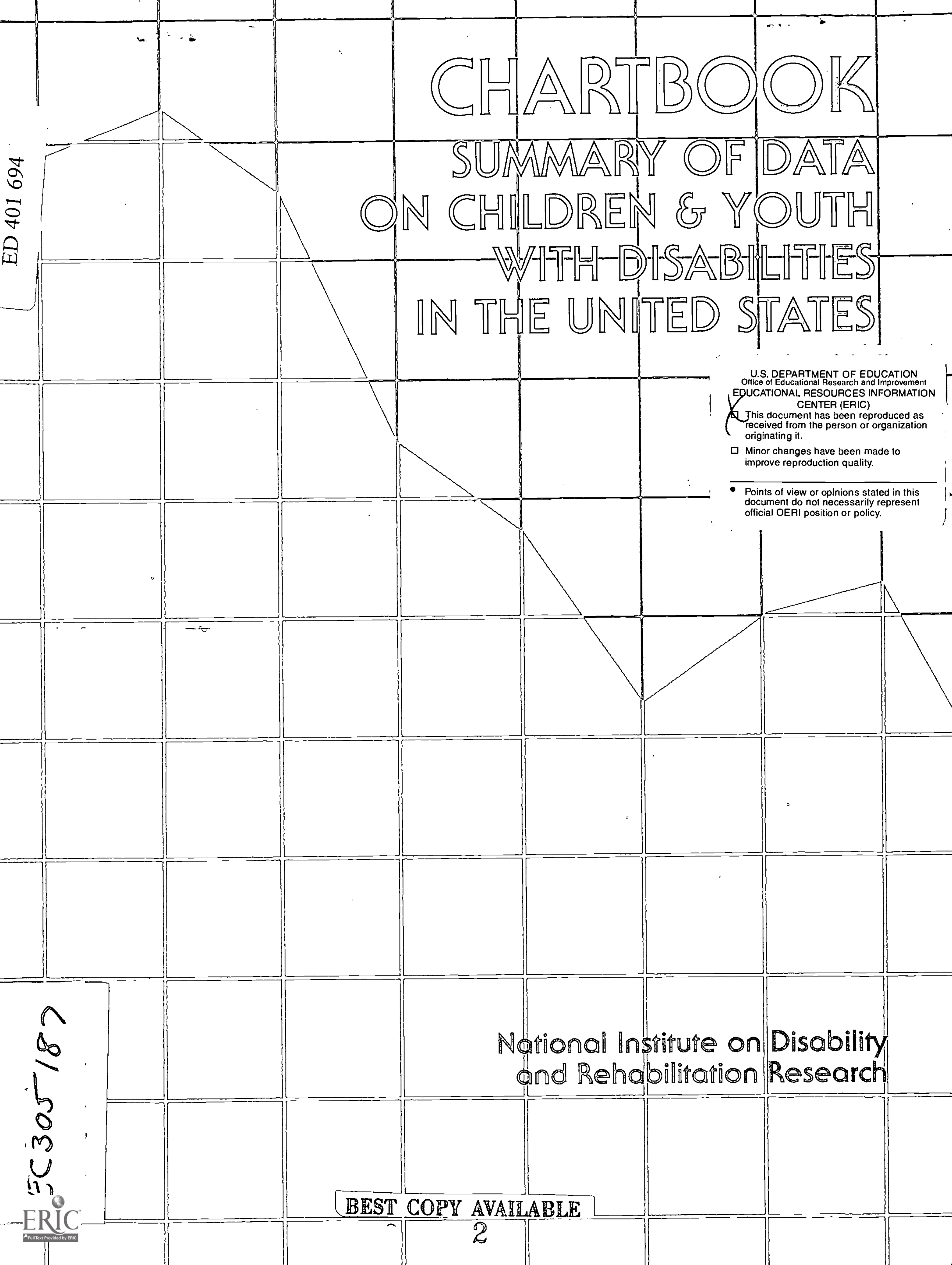
ABSTRACT

This monograph provides a compilation of 1985-1993 statistical data on children and youth with disabilities. Data sources included: (1) national surveys that collect economic and social information; (2) national surveys on health status; (3) health surveillance reports; and (4) program and administrative data from federal programs serving individuals with disabilities. An introduction provides a general overview of concepts and issues in the definition, measurement, collection, and interpretation of data. It highlights major findings pertaining to: the general prevalence of disabilities and chronic conditions in children and youth; health status and health care utilization; children in residential placements and in various educational settings; youth with disabilities in school-to-work transition programs; disabled children and youth receiving various federal benefits; and state-level data on children and youth with disabilities. The extensive tables that follow provide detailed information on prevalence of disability, health care utilization, education, school-to-work transition, federal program data, and state level data. Each table is accompanied by highlights and explanatory notes. The final section consists of an inventory of data sources and includes information on technical aspects of the surveys. (Contains 67 references.) (DB)



CHARTBOOK

SUMMARY OF DATA ON CHILDREN & YOUTH WITH DISABILITIES IN THE UNITED STATES

National Institute on Disability
and Rehabilitation Research

EC305187

SUMMARY OF DATA ON CHILDREN AND YOUTH WITH DISABILITIES

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INTRODUCTION

Background

Disability among children and youth in the United States is a serious social and public health issue. As medical care continues to improve, mortality rates of children have declined. However, many of these survivors are living with serious chronic disabling conditions. Twenty million children and youth live with chronic illnesses (Newacheck & Taylor, 1992), 10.7 million have developmental, learning and emotional problems (Zill & Schoenborn, 1990), and 3.4 million have activity limitations (Disability Statistics Program, December 1991). A significant number of children are now being born with HIV infection and cocaine addiction. These conditions are associated with a range of physical and mental limitations and the numbers are steadily growing.

The effect of these increasing numbers of children with disabilities on the children themselves and on society is significant. Analysis of disability years, a measure of the number of years people survive with disabilities, suggests that childhood disabilities account for 35% of all disability years (Pope & Tarlov, 1991). Children with disabilities use more medical services than other children, resulting in higher health costs for this group. An average of $1406 was spent on each child with a chronic disabling condition compared to $487 for other children. These costs are going up as the number of children with disabilities increases (Newacheck & McManus, 1988). Special education programs showed a 30% increase in enrollment from 1976 to 1992 (Office of Special Education Programs, 1993). As schools are beginning to serve younger children and providing a wider range of mandated services (i.e., assistive technology), their budgets are being stretched to the limit.

Disability is a complex phenomenon. The Independent Living movement, initiated by disability advocates in the early 1970s, asserts that attitudinal and environmental barriers in society are major obstacles to independence and inclusion for people with disabilities. Lack of access to resources and the "medicalization" of services reflect these barriers (Daniels, 1990). Among children, disability has been found to be associated with low socioeconomic status, low educational attainment, lack of access to health care services, generally poorer health, and non-intact families, although the exact nature of these associations has not been clarified by research. These factors form the basis for the "new morbidity model" which seeks to analyze childhood health and disability in terms of the interaction of environment, behavior, biology, and health and social resources (Baumeister, Kupstas, and Woodley-Zanthos, 1993).

Significant legislation has been passed in recent years to increase the participation of people with disabilities, including children with disabilities, in society and support enhanced independence and quality of life. The Americans with Disabilities Act of 1990 (ADA) bans discrimination in employment, public and private transportation, public accommodations, telecommunications, and local and state government activities. It requires public accommodations to become physically and programmatically accessible to individuals with disabilities. The Technology Related Assistance for Individuals with Disabilities Act of 1988 (Tech Act) provides funds for states to increase access to assistive technology devices and services for individuals with disabilities of all ages. These laws reflect the movement toward recognizing the impact of the environment on disability. Attention to such quality of life issues is critical to understanding and measuring disability.

Other recent federal legislation and policy has mandated improved access to services for children with disabilities. The Individuals with Disabilities Education Act of 1990 (IDEA), formerly the Education for All Handicapped Children Act, mandates a free and appropriate public education for all children and youth with disabilities. The 1989 amendments to the Omnibus Reconciliation Act and the 1990 Supreme Court decision in *Sullivan v Zebly*, mandated that for certain services and benefits, a noncategorical rather than a disease-specific approach be applied by federal programs. In *Sullivan*, the court found that the Social Security Administration had denied Supplemental Security Income benefits to children with serious disability because of its reliance on condition lists to determine eligibility. The court ruled that equity could best be accomplished by assessing the consequences of disability on functioning (Stein et al., 1993).

Disability prevention is a national health priority. Specific goals for children were included in the Healthy People 2000 initiative (U.S. Department of Health and Human Services, 1990). These goals are: reducing disabilities, impairments and limitations in activities associated with chronic conditions, and increasing provider services and service systems for children with special health care needs. Valid and reliable data on disability are needed to assess progress in disability prevention.

Despite the significance of disability issues, the increasing prevalence of disabling conditions, and the accompanying annual disability-related expenditures approaching $200 billion, little comprehensive demographic and epidemiologic research on disability has been conducted. Even less research has focused on children with disabilities. Research has shown that conditions leading to disability are different for children under 18 than for adults (LaPlante, 1991b; Disability Statistics Program, December 1991) which suggests the need for research devoted specifically to children and youth.

Currently, there is no regular and systematic collection of data on the population of disabled children and youth in the United States. Studies that are done tend to focus broadly on disability or narrowly on specific programs and services. Because the data are collected for different purposes and with different methods, it is difficult to interpret and compare findings.

Purpose

The purpose of this Summary is to compile existing statistical data on children and youth with disabilities into a single source and to provide guidance in using the data appropriately. Children and youth are defined as any neonate, infant, child, or adolescent under the age of 21. This Summary will:

- present the major sources of data on disabled children and youth in the U.S.
- describe the various definitions of disability used in data collection
- outline issues in the measurement of disability among children
- explain the strengths and limitations of data sources
- identify gaps in current data collection efforts
- provide an overview of current prevalence estimates and characteristics
- describe future needs

Organization of the Summary

The Summary includes an introduction that provides a general overview of concepts and issues in the definition, measurement, collection, and interpretation of data on children and youth with disabilities. The introduction also highlights major findings related to the general prevalence of disabilities and chronic conditions in children and youth; health status and health care utilization; children in residential placements and in educational settings; youth with disabilities in school to work transition; disabled children and youth receiving various federal benefits; and state-level data on children and youth with disabilities.

The tables that follow the Introduction provide detailed information on prevalence of disability, health care utilization, education, school to work transition, federal program data, and state-level data. Each table is accompanied by highlights and explanatory notes to assist the reader in interpreting the data.

The final section consists of the inventory of data sources. These databases are the primary sources of information on children with disabilities. The inventory includes information on technical aspects of the surveys such as definition of variables, sample size, standard error, weighting, and strengths and limitations of the surveys. This section is designed to assist researchers who may be interested in using the data sources for further analysis and to provide detailed information needed to interpret the estimates presented in the tables. Many of the studies cited in this Summary were based on secondary analyses of these primary data sources.

Methodology for Developing the Summary

This report updates the 1985 publication entitled *Summary of Data on Handicapped Children and Youth* (Human Services Research Institute, 1985) and therefore focuses primarily on data collected from 1985 to the present. Several approaches were used to gather information for this report. An extensive literature review was conducted to identify published reports, articles and surveys covering childhood disability statistics. Experts in the field were consulted and a thorough review of statistical sources was completed.

Types of Data Currently Collected

There are four major types of data currently collected: (1) national surveys that collect economic and social information; (2) national surveys on health status; (3) health surveillance reports; and (4) program and administrative data from federal programs serving individuals with disabilities.

The national surveys include the Decennial Census, the Current Population Survey (CPS) and the Survey of Income and Program Participation (SIPP). The Decennial Census is conducted every 10 years by the U.S. Bureau of the Census. The 1990 Census contained two questions about work disability, one question about mobility limitations, and one question on self-care limitations. The CPS is designed to collect information on labor force participation and income. It includes a question on work disability for those over 18 years of age. The SIPP provides detailed information for respondents 15 and older about limiting conditions. Information on children between the ages of 3 and 14 was obtained from their parents.

The national surveys on health status include the National Health Interview Survey (NHIS), the National Health Interview Survey-Child Health Supplement (NHIS-CH), the National Longitudinal Survey of Youth (NLSY), and the Inventory of Mental Health Organizations and General Hospital Mental Health Services (IMHO/GHMHS). The NHIS is a household survey sponsored by the National Center for Health Statistics (NCHS) designed to assess the health status of Americans. It includes questions related to disability such as degree of activity limitation and provides information by demographic variables such as age, race, and sex. The NHIS-CH was last conducted in 1988. Adult respondents were asked about developmental delays, learning disabilities, and emotional or behavioral problems for children under 18 years of age. The NLSY is funded by the National Institute of Child Health and Human Development of the National Institutes of Health. The survey includes a national cross-section of women and their children. Information on conditions limiting regular school attendance, work or play among children is obtained. The IMHO/GHMHS is a comprehensive biennial survey of mental health organizations that includes information on residential treatment centers for emotionally disturbed children.

Health surveillance reports include the Birth Defects Monitoring Program (BDMP) and HIV/AIDS Surveillance which are both administered by the Centers for Disease Control and Prevention (CDC). The BDMP identifies the prevalence of 161 birth defect categories based on discharge information from participating hospitals across the country. The HIV/AIDS surveillance reports contain prevalence of pediatric AIDS cases by exposure category and race/ethnicity.

Federal benefit programs include special education, vocational rehabilitation, Head Start, Postsecondary Student Aid, Supplemental Security Income, Protection and Advocacy for Individuals with Mental Illness, and University Affiliated Programs for Persons with Developmental Disabilities. Data collected by these programs about recipients provide additional information related to eligibility and services.

Definition of Disability

One of the major issues in disability research is the definition of disability. There are two problems facing researchers in this area: the lack of a widely accepted conceptual foundation for the measurement of disability and the variety of operational definitions used in data collection. As a result of these differing terms and definitions, there are various estimates of prevalence that are not comparable. This discussion is based on definitions of disability in adults. It provides an overview of basic terminology in the measurement of disability. A discussion of definitional issues particular to children with disabilities is presented in a later section of this Summary.

Conceptual definitions. Two major conceptual models of disability are cited in the literature: the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (World Health Organization, 1980), and the functional limitation framework developed by Saad Nagi. The ICIDH was designed to provide a framework to organize information about the consequences of disease. It is still being refined, especially with regard to the concept of handicap, to account for environmental factors such as physical and social barriers (Fougeyrollas, 1993).

Both models have four basic concepts. Table A summarizes the concepts (Nagi, 1991).

Table A. Comparison of Concepts in the ICIDH and Nagi Models of Disability	
ICIDH	**Nagi**
Disease - Something abnormal within the individual; etiology gives rise to change in structure and functioning of the body; indicators are symptoms and signs.	**Active Pathology** - Interruption or interference with normal processes and effort of the organism to regain normal state; indicators are symptoms and signs found in attributes of the individual.
Impairment - Any loss or abnormality of psychological, physiological, or anatomical structure or function at the organ level. Indicators are symptoms, signs and awareness of the individual.	**Impairment** - Anatomical, physiological, mental or emotional abnormalities or loss; indicators are symptoms and signs found in attributes of the individual.
Disability - Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or range considered normal for a human being; indicators are disturbance at the level of the person in a wide range of categories including family and occupational roles, communication, personal care, locomotion, and body disposition.	**Functional Limitation** - Limitation in performance at the level of the whole person in activities such as walking, climbing, reaching, reasoning, seeing, and hearing; indicators can be grouped into categories such as physical, mental, emotional, sensory, and communication.
Handicap - A disadvantage resulting from an impairment or disability that limits or prevents fulfillment of a normal role depending on age, sex, and sociocultural factors; indicators are disturbance relative to other people in a variety of categories including orientation, physical independence, mobility, occupation, social integration, and economic self-sufficiency.	**Disability** - Limitation in performance of socially defined roles and tasks related to family, work, community, school, recreation, and self-care within a sociocultural and physical environment.

The ICIDH concepts of disease and impairment are comparable to Nagi's pathology and impairment (Haber, 1990; Nagi, 1991). The major distinction relates to the terms used to describe the effects of conditions on individuals. The ICIDH concept of disability is similar to Nagi's functional limitations in that the focus is on individual performance of basic activities without regard to situational and contextual factors. These activities are frequently characterized in terms of activities of daily living, mobility and self-care limitations, and assistance needs (Haber, 1990).

Both models recognize the influence of the social and physical environments on a person's ability to perform expected activities. In the ICIDH model, handicap focuses on societal disadvantages resulting from impairment or disability that lead to a decrease in the quality of life and Nagi's disability indicates limitations in social role performance (Coster & Haley, 1992; Brown, 1991; Haber, 1990).

The interrelationship of social role limitations and functional limitations makes it difficult to measure either one. An individual with a functional limitation may not experience a social role limitation. For example, a person with paraplegia may hold a job and maintain a household with minimal accommodations. A person who does not have a limitation, but is perceived to have one, may actually experience a social role limitation. For example, an individual who is HIV positive but experiencing no symptoms may be prevented from working because an employer thinks the individual cannot perform.

These conceptual issues affect measurement of disability. Although the terms handicap and disability have been used synonymously in the United States, the preferred terminology now is "individual with a disability." This language places the person first and the disability second, reflecting one of the themes of the Independent Living movement -- that disability is the result of societal barriers rather than an individual's functional capacity. Without clear conceptual underpinnings that are widely accepted, disability statistics will not be able to reflect the state of individuals with disabilities in a comprehensive and meaningful way.

The definition of disability used in the ADA is similar to the definition used in Section 504 of the Rehabilitation Act of 1973. Under the ADA, a person must meet one or more of the following criteria: (a) have a physical or mental impairment that substantially limits one or more of his or her major life activities, (b) have a record of such an impairment, and (c) be regarded as having such an impairment. Major life activities are defined by example and include caring for one's self, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, working, and participating in the community. Substantial limitation is defined as restriction in the conditions, manner, or duration under which life activities can be performed compared to most people. The ADA definition includes aspects of both functional and social role limitations.

Operational definitions. Every type of data collection effort related to disability - social and economic surveys, health surveys, surveillance reports, and federal benefit program reporting - develops an operational definition of disability to meet its specific goals and objectives. Consequently, there are volumes of data that are limited in applicability.

A variety of terms are frequently used in the context of disability measurement. Before outlining specific operational definitions, a brief review of common terminology may be helpful. There is considerable agreement on the meaning of the terms disease, injury, illness, impairment and conditions (Ficke, 1992; LaPlante, 1991a; Brown, 1991; Levine, 1990):

Disease: any disruption of normal bodily processes

Injury: damage inflicted on a body by some traumatic, external force

Illness: the perception of disease or injury by the individual

Impairment: chronic physiological, psychological, or anatomical abnormality of bodily structure or function that results from disease, injury or congenital malformation

Condition: a general term that includes any specific illness, injury or impairment

There is also agreement that chronic conditions and illnesses (present for the long-term) rather than acute conditions and illnesses are relevant to disability since acute conditions usually do not require prolonged behavioral or social adaptations (Haber, 1990). However, the exact length of time considered to be chronic varies from survey to survey.

The NHIS uses the concept of activity limitation - a long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group - to measure disability. The NHIS concept of activity limitations is similar to the ICIDH concept of handicap and Nagi's concept of disability. All these concepts concern limitations in social role performance. The NHIS also assesses activities of daily living and instrumental activities of daily living which are similar to Nagi's functional limitations and ICIDH's disability. LaPlante (1991a) describes the distinction between activity limitations and limitations in activities of daily living as one of limitation in singular actions (ADL, IADL) vs. complex activities (activity limitation).

Operational definitions used in major data sources are described here. Complete information for each data source cited is provided in the data source inventory section.

Activity Limitations

In the NHIS, activity limitation is defined at three levels: (1) inability to carry on a major activity, (2) limitation in amount or kind of major activity, and (3) limitation in nonmajor activity. Major activities considered usual for one's age group are defined as ordinary play for children under 5 years of age, attending school for children 5-17, working or keeping house for persons 18-69, and capacity for independent living (ability to bathe, shop, eat, and care for oneself without assistance of another person) for persons 70 and above. Nonmajor activities include social, civic or recreational pursuits. Work may be included for working age and older adults whose major activity is keeping house or living independently (Adams & Benson, 1992).

Functional Limitations

In the NHIS, questions address the need for personal assistance in activities of daily living (eating, bathing, dressing, getting around the home) and instrumental activities of daily living (everyday household chores, doing necessary business, shopping, or getting around for other purposes) (Adams & Benson, 1992).

In the SIPP, functional limitation is defined as the ability of persons 15 years and over to perform a set of sensory and physical activities. Limitations are ranked as 1 (with difficulty), or 2 (not at all or only with aid). Activities include:

- seeing words and letters in ordinary newspaper print
- hearing what is said in a normal conversation
- having speech understood
- lifting or carrying 10 pounds
- walking up a flight of stairs without resting
- walking 1/4 mile.

The SIPP also uses need for assistance in activities of daily living and instrumental activities of daily living as a measure of disability. ADLs include the basic tasks of getting around inside the home, getting in or out of a bed or chair, taking a bath or shower, dressing, eating, and using the toilet. IADLs are more complex and include going outside the home, keeping track of money or bills, preparing meals, doing light housework, and using the telephone. Mobility limitations are reported separately because assistive devices such as wheelchairs and canes rather than another person are often used to overcome such limitations.

Chronic Conditions

In the NHIS, respondents identify chronic conditions that cause activity limitations. A condition is considered chronic if either (a) it was first noticed three months or more before the reference date of the interview or (b) it is a type of condition generally considered chronic by NCHS regardless of onset, such as diabetes (Adams & Benson, 1992). NCHS uses the following six major categories or checklists of chronic conditions:

- Skin and Musculoskeletal Conditions
- Impairments
- Digestive Conditions
- Genitourinary, nervous, endocrine, metabolic, blood and blood forming systems
- Circulatory Conditions
- Respiratory Conditions
- Miscellaneous Conditions

Federal Programs

Definitions of disability among the numerous federal benefit programs vary widely. They are based on the legislation supporting the program and are designed according to program objectives, not disability concepts. Criteria such as category of disability, age, insurance status, and employment status are often most important. The criteria used to define the same disability categories vary from agency to agency. Often the specific category attached to clients is determined by professionals interpreting the provided criteria, which adds another potential layer of inaccuracy. A detailed explanation of federal disability criteria for reporting purposes is contained in the Inventory of Data Sources.

Defining Disability in Children

Disability in children has typically been defined by diagnostic group. Public programs typically use diagnoses to determine eligibility, service needs, and reimbursement. Stein et al. (1993) identified four major weaknesses of this approach: (1) no listing can include every possible diagnosis therefore overlooking the effect of lower incidence conditions; (2) the reliability of such classifications is unclear as there is variation in the way clinicians label the same symptoms, variation in the way parents label conditions, and low agreement between professionals and parents; (3) children not in the health care system are less likely to have diagnostic labels and may be underrepresented; and (4) listings are inequitable in determining eligibility for programs and services.

The current trend is to move away from diagnostic condition labels toward a focus on function and daily activities (Stein et al., 1993; Thornton et al., 1990). Although this approach is an improvement over diagnostic labels, it is not without its problems. The NHIS-CH used activity limitations to identify disability. While there is general agreement that school is a reasonable social role for children age 5 and older, there is much less agreement about what constitutes valid social roles for preschool children and infants. Play is the social role used for children under 5 by the NHIS. However, it is difficult to determine if a perceived limitation is the result of the child's developmental stage, a parenting style that promotes dependency, or an underlying physical or mental health problem of the child. For infants, social roles and activities are not yet defined so as to be measurable (Levine, 1990).

Other considerations important for defining disability in children include developmental issues and contextual influences. The definition must encompass cultural and social expectations and developmentally appropriate behavior. Since the majority of children's functional activities take place under the supervision of adults and in environments controlled by adults, the functional performance of the child must be considered as a transactional process (Coster & Haley, 1992). However, these considerations are difficult to incorporate into working definitions.

It is also difficult to determine the duration of disability with children. For example, onset may be considered the first time symptoms appeared or the first time a diagnosis is determined. In some cases, there can be quite a lag time from symptoms to diagnosis during which some children may not be identified. The length of time a condition must last to qualify as chronic has varied from three months to one year in surveys. Some current work suggests a one year time frame is better at eliminating recuperation from acute episodes and recurrent acute conditions such as ear infections (Stein et al., 1993).

The National Child Health Assessment Planning Project (NCHAPP) at Albert Einstein in New York has recently developed a survey instrument to be used for a national survey of children with special health needs (Stein & Westbrook, 1993). The definition of ongoing health conditions is non-categorical and specifies origin, duration, and consequences that can be tailored to meet different programmatic and research needs. Ongoing health conditions are disorders that:

1. Have a biologic, psychologic, or cognitive basis, and
2. Have lasted or are virtually certain to last for at least 1 year, and
3. Produce one or more of the following sequelae
   a. limitation of function, activities, or social role in comparison with healthy age peers in the general areas of physical, cognitive, emotional, and social growth and development
   b. Dependency on one of the following to compensate for or minimize limitation of function, activities, or social role
      1) Medications
      2) Special Diet
      3) Medical Technology
      4) Assistive Device
      5) Personal Assistance
   c. Need for medical care or related services, psychologic services or educational services over and above the usual for the child's age, or for special ongoing treatments, interventions, or accommodations at home or in school (p. 345).

Measurement of Disability in Children

The validity and reliability of measures of disability among children are limited by several factors. These include the definition of disability used, biases of adult respondents, and wording of questions. The complexity in defining disability discussed above relates to the validity of measurement. For very young children particularly, work is just beginning to develop appropriate assessments of disability.

Concerns about adult respondent biases have been noted for the NHIS. Adult respondents are more likely to identify conditions that impact the child's activities and are associated with recent medical encounters. They are less likely to report conditions with little functional impact or those considered embarrassing or stigmatizing (Newacheck & Taylor, 1992). For example, in preliminary field testing of the NCHAPP screen, parents denied their child "looked different" even though staff who were present noted the child did have a visible disfigurement (Stein & Westbrook, 1993).

Measures of children's activity limitations have shown considerable differences in reporting between parents and school reports and between parents and medical records (Haber, 1990). A study comparing parent and teacher ratings of learning disability and mental retardation found there was high agreement between parents and teachers on mental retardation. However, only 57% of children identified as having a learning disability by teachers were also identified by parents (Levine, 1990). A NHIS study on interviewing methods found that 35-45% of conditions found in medical records were unreported in household interviews whereas 8-12% of conditions reported in interviews were not found in medical records (Newacheck & Taylor, 1992).

Variations in wording of surveys can lead to different data estimates. For example, during field testing of the NCHAPP, staff found parents reacted negatively to the term "limit," when asked if a condition limited their child. They were likely to respond that as parents they did not limit their child's activity because of the condition, confusing parental action with condition limitations. When staff changed the word from "limit" to "restrict," the misunderstanding did not occur (Stein & Westbrook, 1993).

In order to generate accurate prevalence estimates or to conduct epidemiological studies of disability among children, large sample sizes are required. For example, in the 1984 NHIS that sampled 105,000 persons, 14,571 cases of disability were reported, but only 1,514 were children and only 123 of these children were severely disabled. The lack of adequate sample sizes limits the reliability of estimates based on such data. Suggestions for expanding survey sample sizes such as network surveys and the inclusion of childhood disability measures in the decennial census have been put forth in the literature (Levine, 1990).

New and Planned Sources of Data Collection on Children

The National Center for Health Statistics fielded a disability supplement to the NHIS which began in January 1994 and will continue through 1995. This survey represents a consensus reached by many researchers and policy makers and will provide useful information for estimates of prevalence and for program and policy development (NCHS, 1993). The supplement will include two questionnaires. The first will collect data on impairment, functional limitation, and social disability. The second will obtain extensive information about household members from phase one who experience limitations or have made adaptations due to the presence of a health condition.

A separate questionnaire will be administered for children. A control group of children without special health needs will be included. In the first phase, questions will be asked about developmental milestones for children under 5, and about performance of ADLs for children 6-17. The second phase will include questions on (a) utilization and barriers to utilization of medical and mental health services, assistive devices, case managers, home care services, child care services, and educational and recreational services; (b) functional status including measures of emotional and behavioral development; and (c) impact of the child's health problem on the family. The data will be collected over a two-year period to ensure adequate sample size.

The NCHAPP, funded by the Maternal and Child Health Bureau between 1990-1992, was designed to develop and pilot an innovative national plan for obtaining urgently needed data on children and youth special health care needs. This project developed a non-categorical operational definition of children with special health care needs, developed and field tested a screening instrument to identify this population, and developed and piloted an in-depth survey instrument. Both instruments, with some modifications, are being used in the NHIS Disability Supplement.

In 1993, the National Institute on Disability and Rehabilitation Research funded a new rehabilitation research and training center (RRTC) on disability statistics for five years. The goal of the RRTC is to conduct an integrated program of research, dissemination and training in disability statistics leading to the synthesis of existing knowledge, and the development of new knowledge, research methods, and procedures that will create a better understanding of the scope, nature, and costs of disability in the United States. Statistical research will be conducted in areas such as demography, epidemiology, costs, health services, employment, housing, earnings, benefits, social services, rehabilitation services, and social activity for various populations.

Interpretation and Limitations of the Data

As described earlier, data related to children with disabilities are collected by various agencies for their particular purposes. This leads to varying definitions of disability, various target populations and ultimately, widely differing estimates of prevalence. There is no regular or systematic national data collection on children and youth. There is little coordination among agencies that currently collect data on disabled children and youth. Consequently, the available data are fragmented and incomplete.

There are a number of gaps in the currently available data. First, there is virtually no information on infants and toddlers as a group. They are usually included with preschool children which includes all children under five years of age. Second, there is little information on preschool children. The validity and reliability of the data that are collected is debatable. Third, there is limited information about children and youth who have mental retardation and mental health problems. Fourth, information on institutionalized children (who make up almost half of the those classified as severely disabled in this population) is sparse. Fifth, there is very limited data collected on the use of assistive devices among children (Levine, 1990). The next section presents a brief overview of current data on children and youth with disabilities.

Prevalence and Characteristics of Children with Disabilities

Prevalence refers to the current number of children who have a disability, or the number of conditions existing at a point in time. Prevalence estimates are available through the NHIS, the NHIS-CH, and SIPP. (The Current Population Survey [CPS] has recently collected data on disability, but those data were not yet available in published form). Incidence refers to the number of new conditions or persons with these conditions who have been identified since the last survey. Incidence estimates are available from the Centers for Disease Control and Prevention (CDC) which administers the Birth Defects Monitoring Program (BDMP) which reports data on congenital malformations, and HIV/AIDS Surveillance which reports cases of pediatric and adolescent human immunodeficiency virus (HIV). Published sources also exist for characteristics of children with disabilities. These data present prevalence estimates classified by age, sex, race, ethnicity, and other characteristics.

Each year, between 100,000 and 150,000 infants are born with major birth defects. Of these, 8,000 die during infancy (Erickson, 1993). Most children who survive infancy live with long-term functional limitations and disabilities as a result of birth defects.

Pediatric HIV/AIDS is another source of disability among infants. The CDC reported 4,906 cases of pediatric AIDS through September 1993 (Centers for Disease Control and Prevention, 1993). Most of these cases were due to births to mothers with HIV infection. These infants born with HIV exhibit developmental delays, emotional and behavioral impairments (Levenson & Mellins, 1992). However, because reporting delays vary widely among exposure, geographic, racial/ethnic, and age categories, the CDC figures probably reflect underreporting. One estimate is that for every one child who meets the CDC reporting requirement, there are from two to ten children actually infected with HIV (U.S. Department of Health and Human Services, 1987). The CDC estimates that reporting of AIDS cases is about 85% complete. Regardless of the estimates of underreporting, there is agreement that more children have HIV than are actually reported to the CDC.

As the incidence of pediatric AIDS has increased in recent years, the number of children with hearing loss due to maternal rubella has been steadily decreasing. Children who were born during the rubella epidemic of 1964-65 are beginning to leave school. They represented 16% of children reported to the Annual Survey of Hearing-Impaired Children and Youth in 1982-83 but only 2% in 1991-92 (Schildroth & Hotto, 1993). Trends such as these show the importance of surveillance data in tracking conditions that lead to limitations among children. These data can also be used to plan for the educational needs of these children.

Table B: Children with a disability, by age: 1991-92

Age	Percent with disability	Percent with severe disability
0 - 3	2.2	0.4
3 - 5	5.2	0.7
6 - 14	6.3	1.3
15 - 17	9.3	3.1
0 - 17	5.8	1.4

Table source: McNeil (1993).

The most recent estimate on the prevalence of childhood disability comes from the SIPP. These data indicate that among persons younger than 18 years old, the disability prevalence rate is 5.8%. (McNeil, 1993). Table B shows these data by age. Prevalence estimates from other data sources are presented in the Statistical Tables section.

Chronic Conditions

Most chronic conditions (physical and mental illnesses, diseases and impairments) do not have high risks of disability. In other words, not all children with chronic conditions have associated disabilities. Impairments have the highest risk of disability. Analysis of NHIS data revealed that 8.6% of conditions among children cause activity limitation, 6.1% cause limitation in a major activity, and .3% cause help to be needed in activities of daily living. Mental retardation and cerebral palsy rank highest in risk for disability. Most of the high risk conditions occurring among children are different from those with high risks at all ages, confirming that the epidemiology of disability is different for children and adults (LaPlante, 1991b).

Analyses of chronic condition data from the 1988 NHIS-CH showed that an estimated 31% of children under 18 years of age (almost 20 million) were reported to have one or more chronic conditions. Not all chronic conditions were included in these estimates, most notably those related to mental health, so these estimates are likely low. Among those reporting chronic conditions, 70% had only one condition, 21% had two and 9% had three or more. Approximately 13% of children with one or more chronic conditions were classified as limited in their usual activities. This rate is higher than the 8.6% rate found in earlier studies, but does confirm that a small segment of the population disproportionately shoulders the burden of chronic conditions. Children with chronic conditions who are limited in their usual activities were more likely to have musculoskeletal impairments, hearing and speech impairments, cerebral palsy, diabetes, asthma, epilepsy, and arthritis (Newacheck & Taylor, 1992).

Using the same data, Newacheck, McManus, & Fox (1991) assessed the prevalence and impact of chronic conditions in persons aged 10-17 years. An estimated 31.5% of U.S. adolescents were reported to have one or more chronic conditions. The most commonly reported chronic conditions overall were respiratory allergies, asthma, and frequent or severe headaches. However, there were substantial differences in prevalence of individual conditions among youth (ages 10-13) and older (ages 14-17) adolescents. Overall, 16% of adolescents reported activity limitations. The detrimental impact on activity levels increases substantially with the number of conditions reported. Adolescents (12-17 years only) with one or more chronic conditions had 35% more behavioral problems than adolescents with no chronic conditions. Again, the number of behavioral problems reported increased with the number of conditions reported. Severity levels, both within disease categories and between disease categories must be closely examined to determine the full impact of chronic illness.

In the SIPP, asthma was reported as a chronic condition causing disability in 6% of children up to 17 years and learning disabilities was 30% (McNeil, 1993). In the NLSY, the estimates were reversed, with asthma accounting for 27% and learning disabilities for 7% (Mott & Quinlan, 1991). This difference between the SIPP and NLSY estimates is probably due to the way the question was asked. In NLSY, health conditions and limitations were coded together. For example, a child with asthma may need frequent attention, or treatment from a doctor or regular use of medicine, but may not be limited in his or her activities. In the SIPP survey, parents were first asked if a child has trouble with certain activities, then asked which conditions are responsible for these difficulties.

Zill & Schoenborn (1990) estimated the lifetime prevalence of developmental delays, learning disabilities, or emotional and behavioral problems lasting three months or more using the 1988 NHIS-CH data. Over 10.5 million children under 18 years of age were identified, which makes these conditions among the most prevalent chronic conditions of childhood and adolescence. The overall prevalence rate was 4% for delays in growth or development among children 0-17; 6.5% for learning disabilities among children 3-17; and 13.4% for significant emotional or behavioral problems among children 3-17. These rates may be underestimates of the true prevalence due to lack of parental recognition of these problems, confusion over changing diagnostic terminology, and forgetting of past problems.

Age and Disability

There is a clear association of disability with aging (LaPlante, 1991a; Storck & Thompson-Hoffman, 1991; McNeil, 1993) whether measured by activity limitations or functional limitations. Data from the 1990 NHIS show that only 5.3% of people under 18 were limited in activity while 39% of those over 70 were limited (Disability Statistics Program, December 1991). The likelihood of such difficulties in basic life activities increases with age (less than 1% in the 0-17 age group and over 57% in the 85 and above age group) (Disability Statistics Program, April 1992). The SIPP data in Table C show that prevalence rates increase steadily with age (McNeil, 1993).

Table C: Prevalence of disabilities by age group: 1991-92

Age	Prevalence rate
0 - 17	5.8%
18 - 44	13.6%
45 - 64	29.2%
65 - 74	44.6%
75 - 84	63.7%
84 and over	84.2%

Among studies focusing specifically on children, the relationship between prevalence and age depends on the type of disability. As children grow, their disabilities become more apparent. For example, the prevalence of developmental delay was found to vary little with age, while the prevalence of learning disabilities increased as children reached school age, and the prevalence of emotional and behavioral problems rose with age (Zill & Schoenborn, 1990). Speech defects and digestive allergies were almost twice as prevalent among younger adolescents (10-13 years) while musculoskeletal impairments and arthritis were twice as prevalent among adolescents ages 14 to 17 (Newacheck, McManus, & Fox, 1991). While parents reported that 17% of youth with disabilities first experienced difficulty before they were one year old, nine out of ten youth were reported to have begun having disability-related difficulties before they were 13 years old (Marder & Cox, 1991).

Sex and Disability

The prevalence of disability is generally higher among boys than girls. Among children, boys generally tend to show higher rates of chronic conditions (Newacheck & Taylor, 1992) and limitations in activity (Disability Statistics Program, December 1991; Storck and Thompson-Hoffman, 1991).

Among children less than 18 years old, boys (7.2%) were more likely than girls (4.4%) to have a disability (McNeil, 1993). Learning disabilities are nearly twice as common among boys as among girls, emotional and behavioral problems were more common among boys, and developmental delay showed no significant gender differences although the rate for males was higher. For all three types of problems combined, the prevalence for boys (23%) exceeded that for girls (16%) by 43% (Zill & Schoenborn, 1990).

Ethnicity and Disability

The relationship of ethnicity and disability among children is unclear. The 1988 NHIS-CH data showed that chronic conditions were more prevalent among white than black children, but it was unclear if the difference was due to reporting bias or to underlying differences in health (Newacheck & Taylor, 1992). Aday (1992) found that chronically ill children with special needs were more likely to be white (16%) than black (12%). However, Zill & Schoenborn (1990) reported that black and Hispanic parents reported fewer developmental and behavioral problems than did nonminority parents, although teacher reports and school records suggest that many of these problems are more common among minority children. They suggest that due to lower literacy levels, or lower quality pediatric care and educational counseling, minority parents were less familiar with the terms used in the survey and therefore tended to answer no to the questions.

The NLSY found racial/ethnic variations in the tendency to report health limitations. The most common health problems reported to the NLSY were asthma (27%) and allergic conditions (10%). Of the 27% of children who have asthma, 46% are Hispanic children compared to 23% of white children.

Income Level and Disability

The prevalence of learning disabilities and emotional and behavioral problems decreased as family income increased. There were no significant differences for developmental delays. When all three problems were combined, the proportion of children ages 3-17 with one or more of these problems fell from 22.8% among children in families with incomes below $10,000 to 18.6% among those in families with incomes of $40,000 or more (Zill & Schoenborn, 1990). Although 36% of the general population of youth were in households with incomes of $40,000 or more, only 15% of youth with disabilities were in households with incomes of $38,000 or more (Marder & Cox, 1991). However, little difference was found in the overall prevalence of chronic conditions among adolescents ages 10 to 17 years who were at or below poverty level and those above poverty level (Newacheck, McManus & Fox, 1991).

Family Structure and Disability

Children from single-parent or stepfamilies were 2-3 times more likely to have had emotional or behavioral problems and somewhat more likely to have learning disabilities than children from intact families. Delays in development varied little with family type (Zill & Schoenborn, 1990).

Disability, Health Status and Health Care Utilization

Once prevalence of conditions is determined, studies can determine to what extent a condition limits a child. Some measures of limitations are: restricted activity days, physician contacts, hospital utilization, and use of assistive devices. Health insurance coverage is a critical need for children with disabilities. About three-fourths (76%) of children had private insurance coverage, 11% had Medicaid coverage, and 13% had neither private insurance nor Medicaid coverage (Aday, 1992). Children in families with incomes of less than $25,000 were substantially more likely to be uninsured (23%) compared with children from families with annual incomes of $25,000 or more (6%).

Restricted Activity Days

A restricted activity day is a day on which a person stays in bed, misses work or school, or cuts down on his or her usual activity because of illness, impairment, or injury. Among children of all ages and races, the highest number of restricted activity days are for children who are both limited in activity and in fair or poor health. For these children, the average number per person per year of restricted days ranges from 41.1 for black children ages 5-17 years to 89.9 days for white children under age 5. As a point of comparison, children who are not limited in activity and are in good to excellent health are estimated to have between 5.6 and 9.2 restricted activity days per year (Ries & Brown, 1991).

Physician Contacts

Analyses of health care utilization of chronically ill children with special needs were conducted based on the 1988 NHIS-CH data. This subgroup of children was defined as those with selected chronic illnesses who experienced major limitation in their usual activities and/or serious pain and discomfort due to these conditions. Around 9.6 million (15%) children under 18 with these conditions were estimated to have special needs. About 84% of children with special needs had at least one contact with a physician during the year. The average number of contacts was eight. Children under 5 were more likely to have seen a physician than those 5-17 (Aday, 1992).

Ries & Brown (1991) used the combined sample from the 1984 to 1988 NHIS and analyzed health care utilization by health status. Their estimates for physician contacts ranged from 2.8 per child per year for children 5-17 years old who were not limited in activity and in good to excellent health, to 28.2 per child per year for children under 5 years who were limited and in fair or poor health.

Data from the National Longitudinal Survey of Youth (NLSY) showed that the percentage of children requiring attention or treatment of a problem by a doctor or other professional was 5% (Mott & Quinlan, 1991).

Hospital Utilization

Around 9% of chronically ill children with special needs had been hospitalized for their conditions at least once during the year. Those who averaged the fewest doctor visits (black children, low income children, and children covered by Medicaid) were also the most likely to have been hospitalized (Aday, 1992). In addition, children with birth defects comprise almost one-third of pediatric hospital admissions (Sever, Lynberg & Edmonds, 1993).

Assistive Devices

Data from the 1990 NHIS show that more than 13 million Americans use assistive devices, the majority of devices being used to assist with mobility limitations. Most people who use assistive devices are over 65. Persons under 24 account for 8% of device use. (LaPlante, Hendershot, & Moss, 1992).

The NLTS reported assistive device use by special education students ages 13 to 21. Overall, fewer than 2% of students with disabilities use assistive devices. However, these estimates vary widely depending upon the impairment. For example, of the 2% of students with disabilities who used wheelchairs, 45% had orthopedic impairments. Hearing aids were the most common assistive device used by hearing impaired students. Among students with visual impairments, Braille or large print readers, opticon or optical scanners, and computers to aid vision were the most frequently used (Valdes, Williamson, & Wagner, 1990).

Children in Residential Placements

Children and youth in state institutions are decreasing more rapidly than the general state institution populations. This shift toward providing care for children within the home while providing them with a free and appropriate public education has been the impetus for declining residential population among children with mental retardation/developmental disabilities (MR/DD).

State institutions include state-operated facilities for persons with mental retardation and related conditions with 16 or more residents or distinct units for persons with mental retardation and related conditions within state institutions primarily serving other populations.

There has been a 90% reduction in the number of children age 21 years and younger in state MR/DD institutions between 1965 and 1991. On June 30, 1991, only 6,944 state institution residents (8.7% of the total) were 21 years or younger. This compares with 54,130 persons 21 years or younger living in state institutions on June 30, 1977 (35.8% of the total) and 91,590 in 1965 (48.9% of total). Children who were 14 years or younger made up only 2.3% of state institution populations in 1991. In 1992, a total of 10 states had no state institution residents who were younger than 15 years old (Lakin, Blake, Prouty, Mangan, & Bruininks, 1993).

Within state institutions, residents who are younger have more severe cognitive limitations than older residents. For example 79% of state institution residents 14 years and younger had profound mental retardation compared with 64% of the state institution residents older than 14 years (Lakin et al., 1993).

Besides state institutions for MR/DD, residential treatment is provided by residential treatment centers (RTCs) for emotionally disturbed children. The number of RTCs for emotionally disturbed children rose from 261 in 1970 to 368 in 1980, declined to 322 in 1984, but then increased substantially to 440 in 1988. Part of this latter increase resulted from the addition to the survey of a number of RTCs not previously identified. Thus, part of the increase was actual, and part resulted from a more complete coverage of the universe of RTCs.

The number of RTCs providing outpatient services was more than two and a half times greater in 1988 than in 1970, increasing from 48 RTCs in 1970 to 130 in 1988, with only a slight decline occurring between 1980 and 1984. This increase paralleled the increase in total number of reported RTCs. The number of RTCs with partial care services increased from 44 in 1970 to 156 in 1988.

Education

The Individuals with Disabilities Education Act (IDEA) ensures that a free, appropriate public education comprising special education and related services be provided to all children and youth with disabilities. The Elementary and Secondary Education Act (ESEA), Chapter 1, State Operated Programs (SOP), mandates provision of services to children and youth with disabilities from birth to age 21. Data on children served in public education are from the IDEA annual report to Congress. A total of 4,994,169 children from birth through age 21 with disabilities were served during the 1991-92 school year under the IDEA Part B and Chapter 1 (SOP) programs (Office of Special Education Programs, 1993). The 1991-92 school year was the first time national data were collected on children with autism and traumatic brain injury.

The needs of infants and toddlers with disabilities are met under Part H of the IDEA. Part H was created in 1986, and fiscal year 1991 was the first year of full implementation after the phase-in period. Through state grants, services are provided to children under the age of three who meet the State's eligibility criteria for Part H, including infants and toddlers who are at risk, if a State chooses to serve these children and their families.

The Preschool Grants Program, Section 619 of IDEA, requires States to provide a free appropriate education to all eligible three and five year olds with disabilities. Like Part H, this program also had its first full year of implementation in fiscal year 1991. States are implementing programs that reflect the unique needs of this age group and developing appropriate transitions into and out of preschool.

Children and youth with disabilities are also served in separate day and residential facilities, and in Head Start programs. Children served at separate day and residential facilities are only a small proportion of all disabled children. However, they tend to be more severely disabled than children who attend regular schools. Although the number of students in separate institutions has declined in recent years, students who receive education in separate schools has remained relatively constant, at about 7% of all students with disabilities. (Stephens, Lakin, Brauen, & O'Reilly, 1990).

In Head Start, 10% of program enrollment must include children with disabilities. Before a child with disabilities is accepted for Head Start, he or she must be diagnosed by a qualified professional. In program year 1989-1990, Head Start provided developmental services to 69,267 children, or 13% of its total enrollment. Of the children with disabilities enrolled in Head Start, 67.2% have been diagnosed as speech impaired. This is by far the largest category of children with disabilities served in Head Start programs. The next largest categories of children are those with health impairments (11%) and those with learning disabilities (5.9%) (Head Start Bureau, 1992).

The Office for Civil Rights (OCR) within the Department of Education is charged with ensuring compliance with civil rights laws that prohibit discrimination in education. Its 1990 annual survey estimated that one-half of the students enrolled in special education as of October 1990 were children with learning disabilities (Office for Civil Rights, 1993). One-quarter were hearing impaired. The other categories of disability each accounted for 10% or less of the total enrollment in special education.

The Annual Survey of Deaf and Hard of Hearing Children and Youth conducted annually by the Center for Assessment and Demographic Studies at Gallaudet University provides data on deaf students and their educational characteristics. Most students (66%), received their education in regular schools for hearing students and 21% were in residential schools for deaf students (Center for Assessment and Demographic Studies, 1993).

Data from the 1988 National Health Interview Survey of Child Health showed that of children ages 6-17, 8% of all children received special education services because of delays in growth or development (1%), learning disabilities (5%), or emotional or behavioral problems that lasted 3 months or more (2%) (Zill & Schoenborn, 1990).

The statistical data on the number of students with learning disabilities indicate that since the inclusion of learning disabilities as a new disability in 1976-77, the number of students served has grown by 160%. Although it is generally believed that this increase is a result of misidentification, the increase may be explained by socio-cultural changes such as increases in poverty, increases in substance abuse among pregnant women, lack of social support, and more single-parent families (Hallahan, 1992).

For students in post-secondary institutions, the National Postsecondary Student Aid Study used student self-reports to measure disability. During academic year 1989-90, 7% of undergraduates reported that they had some type of disability (National Center for Education Statistics, 1993). Because the measure of disability was self-reported, there is the potential for overreporting or underreporting of disability status. According to data collected by the Survey on Deaf and Hard of Hearing Students in Postsecondary Education, 47% of the nation's 5000 two-year and four-year postsecondary education institutions enrolled one or more students who identified themselves to the institution as deaf or hard of hearing in academic years 1989-90 through 1992-93 (Lewis & Farris, 1994). Of the estimated 20,040 students that institutions could identify as deaf or hard of hearing who were enrolled in academic year 1992-93, there were 4,520 deaf students, 7,770 hard of hearing students, and 7,750 students in the combined deaf or hard of hearing category. This latter category was for institutions that did not distinguish between deaf and hard of hearing students.

School to Work Transition

The transition from school to work is a major adjustment for all students, but particularly those with disabilities. The transition requires new challenges to independence including where to live and where to work. Whereas education is guaranteed for all students with disabilities, not all persons with disabilities are eligible for the employment services that vocational rehabilitation (VR) programs provide. According to the 1990 U.S. Current Population Survey, an estimated 9% (14.2 million) of Americans between the ages of 16 and 64 have a work disability. Of youth ages 16-24, 1.8% are limited in the amount or kind of work they can perform (Disability Statistics Program, May 1992).

The primary source of information on youth with disabilities in secondary education is the National Longitudinal Transition Study of Special Education Students (NLTS). Mandated by Congress in 1983, this study was designed to provide longitudinal information on the experiences of youth with disabilities in their transition from secondary school to early adulthood. A series of statistical almanacs and research reports describes social experiences, school programs, school characteristics and policies, school achievement and completion, employment characteristics, postsecondary education participation, services provided by the school and other sources, parental expectations for youth in education, employment, and independence.

School to work transition begins with completion of education. Data reported by the states to the Office of Special Education Programs (OSEP) for school year 1990-91 indicate that 46% of students with disabilities exiting the educational system received a diploma. Another 13% graduated with a certificate of completion or credential other than a regular diploma and 23% dropped out (Office of Special Education Programs, 1993). The NLTS estimated that of special education students who were out of school at the time of data collection in 1987, 56% had graduated (of these, 75% received a regular diploma), and 33% dropped out. Estimates were based on school records and parent interviews (Valdes, Williamson, & Wagner, 1990).

Once students leave school, even the most independent were still in need of support services. One in five youth who had achieved the most independence were estimated to need occupational therapy or life skills training (Wagner, 1992). Youth with less independence had an even greater need for occupational services as well as assistance such as interpreters, speech therapy, personal counseling, and physical therapy or mobility training.

For students who are ready for employment, the state-federal vocational rehabilitation program (VR) is a potential source of assistance. Through transition planning at their secondary schools, students are evaluated for their eligibility for VR services. Unlike special education which is mandated for all students with disabilities, VR requires that the applicant meet eligibility criteria in addition to the disability. Under the Rehabilitation Act Amendments of 1992, to be eligible for VR services, the individual must require VR services to prepare for, engage in, or retain gainful employment. In addition, VR programs are mandated to give preference to applicants with severe disabilities. Table E describes the characteristics of youth who applied and were accepted for VR services.

Table D. Primary Disability of Youth Applicants to VR and Youth Accepted for VR Services: 1990

Primary Disability According to VR	Percent of Youth Applicants	Percent of Youth Accepted for VR	Percent Difference from Applicants
Visual Impairment	4.4	4.9	+0.5
Hearing Impairment	6.8	8.3	+1.5
Orthopedic impairment	5.7	6.9	+1.2
Mental illness	6.0	6.0	0.0
Mental retardation	42.2	41.0	–1.2
Learning Disability	26.5	24.1	–2.4
Other	8.4	8.9	+0.5

Table source: Wine, Hayward, & Wagner (1993), Tables 4 and 11.

The largest percentages of applicants to VR were youth with mental retardation (42.2%) and youth with learning disabilities (26.5%). Youth with visual impairments were the least common applicants to VR (4.4%). Among youth who were accepted for services, the distribution of primary disabilities was very similar to that for the overall group of applicants. The distribution of primary disabilities shows only slight differences, with smaller percentages of youth with mental retardation and learning disabilities accepted for services than applying for them.

Of the youth clients successfully rehabilitated under VR programs, 74% entered full-time or part-time competitive employment, but placement patterns differed depending on the severity of the disability (Wine, Hayward, & Wagner, 1993).

Whether or not they received VR services, men and women who were employed were distributed differently among occupational categories, with women more likely than men to be clerical or service workers. Women were also less likely than men to be craft workers or laborers. In addition, patterns of employment over time showed that one third of youth with disabilities were employed in both 1987 and 1990, but rates ranged from 47% of youth with learning disabilities to 9% of those with multiple impairments. Almost 75% of youth with orthopedic or multiple impairments or who were deaf/blind were not employed in either 1987 or 1990, compared to an overall unemployment rate of 30% for all youth with disabilities during that time period. (D'Amico & Blackorby, 1992)

Federal Benefit Programs

The primary program of federal benefits for disabled children and youth is Supplemental Security Income (SSI). In 1992, an estimated 623,845 blind and disabled children received a $611 average monthly payment (Social Security Administration, 1993). Table E shows the number and percent of blind and disabled children receiving SSI payments as of December 1992.

Table E. Number and Percent of Blind and Disabled Children Receiving Federally Administered Supplemental Security Income (SSI) Payments, By Age: December 1992

Age	Total	Blind	Disabled
Total number	623,845	9,402	614,443
Total percent	100.0	100.0	100.0
Under 5	16.0	15.0	16.0
5 - 9	26.9	25.5	26.9
10 - 14	30.6	26.8	30.6
15 - 17	15.7	15.1	15.7
18 or older	10.8	17.5	10.7

Table source: Social Security Administration (1993), Table 7.E2.

University Affiliated Programs for Persons with Developmental Disabilities were established to provide evaluation and services to persons with developmental disabilities and their families. In fiscal year 1991, 83% of the clinic-based clients served by UAPs were children and youth ages 0 to 21 (NIRS, 1991).

State-level Data

Newacheck (1991) used synthetic estimation to produce state level estimates of chronic conditions that result in activity limitations from the National Health Interview Survey data from 1985-1989 for children and youth under 22. Findings reveal that 5.3% of U.S. children and youth under 22 were estimated to have experienced activity limiting chronic conditions during 1985-1989, or 4.1 million children annually. Activity-limiting chronic conditions were most prevalent in the Midwest and least prevalent in the Northeast (Newacheck, 1991).

Future Needs

There are a number of difficulties in collecting statistical data on children and youth with disabilities that need to be addressed in the future to generate a valid, reliable knowledge base. Much more extensive data are needed for effective policy development, program planning and accountability, and service delivery outcomes. A national disability surveillance system has been recommended by the Committee for a National Agenda for the Prevention of Disabilities. Such a system would monitor incidence and prevalence of disabilities and secondary conditions resulting from primary disabilities. Monitoring of causal phenomena, risk factors, and quality of life would also be included (Pope & Tarlov, 1991).

The conceptual models must be further developed particularly as they relate to children. Testing on the validity and reliability of these concepts as operationalized in surveys must be conducted. Consensus on the concepts to be measured and the corresponding operational definitions must be generated to develop standard measures of disability (Pope & Tarlov, 1991).

In terms of methodology, issues related to proxy respondents and the wording and structure of surveys need to be studied to determine their effects on reported rates of disability. Innovative ways to increase sample sizes and reduce sampling error to improve the quality of national, regional and state-level estimates of prevalence need to be developed. It should also be recognized that the universe of disability continues to expand. This expanding universe of disability is resulting from the changing causes and patterns of disability, including but not limited to: violence, HIV, aging, substance abuse, environmental illness, and stress. In the future, these populations will need to be described in terms of socioeconomic, educational, ethnic/cultural, and geographic factors, and by the disability related consequences of these conditions, including functional loss, employment and social behavior.

A coordinated effort at the federal level is needed to develop a plan to collect comprehensive data on all children and youth with disabilities on a regular basis. This includes data on children in institutions as well as households, children of all ages, children with all types of health conditions and disabilities at all levels of severity including HIV/AIDS. A major effort is needed to institute longitudinal studies of children with disabilities to examine the impact of disabilities on children and society over time (Levine, 1990; Pope & Tarlov, 1991). Special attention is needed to understand transitions, medical care utilization and expenditures, and use of assistive devices and other technology in ameliorating the effects of disabilities.

STATISTICAL TABLES

This section of the Summary presents detailed statistical tables from various data sources. Most of the data presented are from sample surveys and therefore the estimates are subject to sampling variability. Sampling variability occurs when estimates are based on sample data rather than the entire population of interest. Estimates based on samples may differ from figures that would have been obtained had the entire population been used. The standard error is a measure of sampling variability. Estimates derived from small sample sizes tend to have large standard errors and are therefore unreliable. These estimates should be interpreted with caution. In some sources, authors have omitted estimates that are based on sample sizes of fewer than 30 because the large standard error makes the estimate unreliable.

Statistics based on federal reporting requirements, or child counts, represent the entire population of interest, for example, all children receiving special education services in a given school year, or the number of cases of HIV reported to AIDS surveillance. While not subject to sampling variability, the data presented can still be incomplete or biased. Although most programs specify definitions and guidelines, these data sources are still subject to underreporting and misclassification. The possible sources of bias for each data source are described in the explanatory notes for each table and also in the inventory section.

Tables are reproduced from the original sources. Information on standard errors of the estimates have been omitted, but are available in the original source material cited at the bottom of each table. When presenting findings from various surveys, we retained the terminology used in the original survey.

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PREVALENCE AND CHARACTERISTICS OF CHILDREN WITH DISABILITIES

Table 1. Mean Annual Percent Change in the Rates of Selected Malformations: 1979-1989

HIGHLIGHTS

- Between 1979 and 1989, birth prevalence of 27 defects was increasing, prevalence of two defects was decreasing and prevalence of nine defects had remained stable. Prevalence was considered stable if the mean annual rate change was less than 2%. Almost half of the increasing defects were cardiac defects.

- Increases in birth defects such as Trisomy 18 (8.3%) and fetal alcohol syndrome (12.2%) may be due to better clinical awareness and recognition of these malformations.

- Two noteworthy decreasing defects are anencephalus (–6.4%) and spina bifida (–3.4%). Possible reasons for these decreases are the impact of prenatal diagnosis, particularly on anencephalus, and maternal lifestyle changes, such as better nutrition, which may decrease the risk of these defects. Several reports have suggested that the use of periconceptional multivitamins may contribute to the reduction of the birth prevalence of anencephaly and spinal bifida.

EXPLANATORY NOTES

These data are from the Birth Defects Monitoring Program/Commission on Professional and Hospital Activities (BDMP/CPHA), which is a national program to monitor congenital malformations by using hospital discharge data on newborns. Edmonds & James (1993) analyzed 38 malformations from 161 reported birth defects categories. They chose 1979 as the starting year because that was the year the International Classification of Diseases, ninth revision, clinical modification (ICD-9-CM) codes for such defects as fetal alcohol syndrome were included in the database. The 38 malformations were selected because they occur in sufficient numbers to provide relatively stable rates, affect different organ systems, and are of sufficient severity or frequency to be of public health concern.

For each defect, the geometric mean annual percent change in rate was computed for the nine years between the midpoints of these two periods. The authors categorized a defect as increasing it its mean annual rate change was at least 2%. A defect was categorized as decreasing if its mean annual percent change was at least –2%.

Table 1. Mean Annual Percent Change in the Rates of Selected Malformations: 1979-1989

Defects	Cases		Rates (cases per 10,000 total births)		Mean annual percent change
	1979-1980	1988-1989	1979-1980	1988-1989	
CENTRAL NERVOUS SYSTEM					
Anencephalus	624	187	3.47	1.92	−6.4
Spina bifida without anencephalus	919	363	5.11	3.74	−3.4
Hydrocephalus without spina bifida	782	537	4.34	5.53	2.7
Encephalocele	198	94	1.10	0.97	−1.4
Microcephalus	382	340	2.12	3.50	5.7
EYE					
Anophthalmos/Microphthalmos	102	78	0.57	0.80	3.8
Congenital cataract	128	124	0.71	1.28	6.8
Coloboma of eye	37	31	0.21	0.32	4.8
Aniridia	13	7	0.07	0.07	0.0
CARDIOVASCULAR					
Common truncus	35	35	0.19	0.36	7.4
Transposition of great arteries	157	192	0.87	1.98	9.6
Teratology of fallot	132	164	0.73	1.69	9.8
Ventricular septal defect	2042	2160	11.34	22.23	7.8
Atrial septal defect	209	674	1.16	6.94	22.0
Endocardial cushion defect	62	127	0.34	1.31	16.2
Pulmonary valve atresia and stenosis	104	346	0.58	3.56	22.3
Tricuspid valve atresia and stenosis	29	29	0.16	0.30	7.2
Aortic valve stenosis and atresia	39	78	0.22	0.80	15.4
Hypoplastic left heart syndrome	100	111	0.56	1.14	8.2
Patent ductus arteriosus	3216	4251	17.87	43.75	10.5
Coarctation of aorta	133	131	0.74	1.35	6.9
Pulmonary artery anomaly	201	250	1.12	2.57	9.7
RESPIRATORY					
Lung agenesis and hypoplasia	298	373	1.66	3.84	9.8
OROFACIAL					
Cleft palate without cleft lip	909	540	5.05	5.56	1.1
Cleft lip with or without cleft palate	1397	861	7.76	8.86	1.5
GASTROINTESTINAL					
Tracheo-esophageal anomalies	335	258	1.86	2.65	4.0
Rectal and intestinal atresia	581	377	3.23	3.88	2.1
GENITOURINARY					
Renal agenesis and dysgenesis	221	240	1.23	2.47	8.1
Bladder exstrophy	53	28	0.29	0.29	0.0
MUSCULOSKELETAL					
Clubfoot without CNS defects	4612	2335	25.62	24.03	−0.7
Reduction deformity upper limbs	275	139	1.53	1.43	−0.7
Reduction deformity lower limbs	140	78	0.78	0.80	0.3
Congenital arthrogryposis	239	206	1.33	2.12	5.3
CHROMOSOMAL					
Trisomy 13	84	90	0.47	0.93	7.9
Down syndrome	1373	926	7.63	9.53	2.5
Trisomy 18	123	135	0.68	1.39	8.3
OTHER					
Fetal alcohol syndrome	198	301	1.10	3.10	12.2
Rh hemolytic disease	2730	1287	15.17	13.24	−1.5

Table source: Edmonds & James (1993), Table 3.1; Data source: Birth Defects Monitoring Program.

Table 2. Pediatric AIDS Cases by Exposure Category and Race/Ethnicity, Reported Through September 1993

HIGHLIGHTS

- The highest proportion (88%) of all pediatric AIDS cases reported to the CDC through September 1993 were due to the mother at risk for HIV infection. Of these 4,328 cases, 1,920 involved the mother at risk by injecting drug use.

- Blood transfusions accounted for only 7% of pediatric AIDS cases.

EXPLANATORY NOTES

All 50 states, the District of Columbia, U.S. dependencies and possessions, and independent nations in free association with the United States report AIDS cases to Centers for Disease Control and Prevention (CDC) using a uniform case definition and case report form.

Reporting delays (time between diagnosis and report to CDC) vary widely among exposure, geographic, racial/ethnic, and age categories, and have been as long as several years for some cases. About 55% of all cases are reported within three months of diagnosis, but about 20% are reported more than one year after diagnosis. Although completeness of reporting of diagnosed cases varies by geographic region and population, studies conducted by state and local health departments indicate that reporting of AIDS cases in most areas of the United States is more than 85% complete.

Age group tabulations are based on the person's age at the time of diagnosis of AIDS. Pediatric cases include children under 13 years of age.

Table 2. Pediatric AIDS Cases by Exposure Category and Race/Ethnicity, Reported Through September 1993

	White, not Hispanic		Black, not Hispanic		Hispanic		Asian/Pacific Islander		American Indian/Alaska Native		Total	
Exposure Category	N	%	N	%	N	%	N	%	N	%	N	%
Hemophilia/coagulation disorder	141	14	24	1	33	3	3	14	1	7	202	4
Mother with/at risk for HIV infection:	663	68	2556	95	1074	90	10	45	13	93	4328	88
Injecting drug use	290		1133		483		3		6		1920	
Sex with injecting drug user	132		390		318		2		2		846	
Sex with bisexual male	39		28		20		1		-		88	
Sex with person with hemophilia	13		5		3		-		-		21	
Born in Pattern-II[1] country	3		300		2		-		-		305	
Sex with person born in Pattern II country	-		22		1		-		-		23	
Sex with transfusion recipient with HIV infection	6		5		8		-		-		19	
Sex with HIV-infected person, risk not specified	45		148		77		1		2		275	
Receipt of blood transfusion, blood components, or tissue	29		43		25		1		-		98	
Has HIV infection, risk not specified	106		482		137		2		3		733	
Receipt of blood transfusion, blood components, or tissue	167	17	74	3	76	6	9	41	-	-	327	7
Risk not identified[2]	9	1	29	1	11	1	-	-	-	-	49	1
Total	980	100	2683	100	1194	100	22	100	14	100	4906	100

[1] Pattern II transmission is observed in areas of sub-Saharan Africa and in some Caribbean countries.

[2] Refers to persons whose mode of exposure to HIV is unknown. This includes persons under investigation; persons who died, were lost to follow-up, or declined interview; and persons whose mode of exposure to HIV remains unidentified after investigation.

Table source: Centers for Disease Control and Prevention (1993), Table 6.

Data source: HIV/AIDS Surveillance

Table 3. AIDS Cases in Children by Sex, Age at Diagnosis, and Race/Ethnicity, Reported Through September 1993

HIGHLIGHTS

- As of September 30, 1993, there were 19,030 children and youth through age 24 diagnosed with AIDS who had been reported to the Centers for Disease Control and Prevention (CDC).

- AIDS cases for boys and girls under age 5 are similar. But for every other age group, reported cases among boys are much higher than for girls in the same age group. The difference is especially pronounced among the 20-24 age group, where the male AIDS prevalence (10,071 reported cases) is nearly five times that of female youth (2,641 reported cases).

EXPLANATORY NOTES

Reporting delays (time between diagnosis and report to CDC) vary widely among exposure, geographic, racial/ethnic, and age categories, and have been as long as several years for some cases. About 55% of all cases are reported within three months of diagnosis, but about 20% are reported more than one year after diagnosis. Although completeness of reporting of diagnosed cases varies by geographic region and population, studies conducted by state and local health departments indicate that reporting of AIDS cases in most areas of the United States is more than 85% complete.

Age group tabulations are based on the person's age at the time of diagnosis of AIDS.

Table 3. AIDS Cases in Children by Sex, Age at Diagnosis, and Race/Ethnicity, Reported Through September 1993

Age at Diagnosis	White, not Hispanic	Black, not Hispanic	Hispanic	Asian/Pacific Islander	American Indian/Alaska Native	Total
Male						
Under 5	329	1,167	478	8	8	1,992
5 - 12	248	183	155	7	1	594
13 - 19	473	299	186	11	11	980
20 - 24	4,735	3,282	1,938	75	23	10,071
Male subtotal	5,785	4,931	2,757	101	43	13,637
Female						
Under 5	320	1,143	455	1	5	1,933
5 - 12	81	189	106	6	0	384
13 - 19	102	262	68	1	1	435
20 - 24	672	1,347	594	12	10	2,641
Female subtotal	1,175	2,941	1,223	20	16	5,393
Total	6,960	7,872	3,980	121	59	19,030

Table source: Centers for Disease Control and Prevention (1993), Table 8.

Data source: HIV/AIDS Surveillance

Table 4. Prevalence of Chronic Conditions Causing Activity Limitations Among Noninstitutionalized Persons Under 22 Years of Age: 1985-1989.

HIGHLIGHTS

- Of all U.S. children and youth under 22 years old, 5.3% were estimated to have experienced activity limiting chronic conditions during 1985-1989. On an annual basis, 4.1 million children and youth were limited in their activities by chronic conditions. Activity-limiting chronic conditions were most prevalent in the Midwest and least prevalent in the Northeast.
- Nationally, respiratory diseases (principally asthma) represented the leading cause of activity limitation among children and youth. Respiratory conditions accounted for 21% of all cases of activity limitation. The second leading cause of activity limitation was mental retardation, which accounted for 17% of all cases of activity limitation. Other mental and nervous disorders ranked third and accounted for 13% of all cases. Together, respiratory disease, mental retardation, and other mental and nervous system disorders accounted for approximately half of all reported cases of activity limitation.

EXPLANATORY NOTES

The information in this table is based on the National Health Interview Survey. To increase precision of the estimates, five years of survey data, from 1985 to 1989, were combined. The combined NHIS sample included 173,728 children and youth under age 22. The average response rate for all years exceeded 95% and overall prevalence levels were similar for each of the five years.

Table 4. Prevalence of Chronic Conditions Causing Activity Limitations Among Noninstitutionalized Persons Under 22 Years of Age: 1985-1989

Condition Group	United States Prevalence per 100,000	Northeastern United States Prevalence per 100,000	Midwestern United States Prevalence per 100,000	Southern United States Prevalence per 100,000	Western United States Prevalence per 100,000
All conditions	5261	4902	5563	5336	5106
Impairments					
Blindness, impairment of vision	86	97	81	87	79
Deafness, impairment of hearing	202	191	243	161	231
Impairment of speech	281	200	308	341	223
Mental retardation	909	931	1046	923	700
Paralysis, complete or partial	156	137	147	150	193
Deformities, nonparalytic orthopedic impairments, other	679	582	790	632	714
Diseases					
Infective, parasitic diseases	27	30	22	27	29
Endocrine, nutritional metabolic, blood disorders	144	112	131	194	106
Mental, nervous system disorders	703	679	732	712	675
Diseases of eye, ear	185	139	216	177	205
Diseases of circulatory system	175	180	173	177	170
Diseases of respiratory system	1113	1076	1093	1102	1191
Diseases of digestive system	70	70	57	79	69
Genitourinary disorders, pregnancy, childbirth	56	39	41	89	33
Diseases of skin, subcutaneous tissue	50	28	45	63	55
Diseases of musculoskeletal system, connective tissue	148	145	154	139	157
Other	277	266	283	282	274

Table source: Newacheck (1991), Table 1.

Data source: National Health Interview Survey, 1985-1989

Table 5. Number and Percent of Chronically Ill Children and Those with Special Needs by Condition: 1988

HIGHLIGHTS

- The highest prevalence of children age 17 years and under with chronic illness included in the 1988 NHIS-CH included hay fever or respiratory allergies (9.2% or 5.8 million), frequent or repeated ear infections (9% or 5.7 million), and asthma (4.2% or 2.7 million).

- Conditions experienced by 2 - 3% of children (or 1.3 to 1.8 million) included frequent or severe headaches (2.8%), digestive allergies (2.5%), frequent diarrhea or bowel trouble (2%), or other conditions (2.3%).

- Conditions that occurred in less than 2% of children (or less than 1 million) were: heart disease, musculoskeletal impairments, arthritis, anemia, epilepsy, cerebral palsy, diabetes, and sickle cell anemia.

- The chronic conditions for which more than half of the children experience activity limitation and bother were cerebral palsy (90.9%), frequent or severe headaches (76.3%), epilepsy or seizures (65.5%), asthma (65.3%), frequent or repeated ear infections (63.5%), arthritis or other joint problems (62.1%), and other musculoskeletal impairments (59%).

EXPLANATORY NOTES

These data are from the National Health Interview Survey on Child Health (NHIS-CH) conducted in 1988 by the National Center for Health Statistics. Data were collected from a nationally representative sample of children 17 years of age and under.

The children represented in this table were identified to have had one or more of a number of childhood conditions in the NHIS-CH condition record. Respondents were asked whether the child had ever had the condition; if so, whether they had it in the last 12 months. For selected conditions, those who had experienced it in the last year were asked whether it had lasted at least 3 months.

For conditions that met these criteria, the respondent was asked whether the child missed any school, stayed in bed, or otherwise limited usual activities. Also asked was how much pain, discomfort, or bother the child has experienced during the past 12 months due to the condition. The respondent was also asked the number of nights, if any, the child has been hospitalized, the number of times a medical professional was consulted about the child's condition, and if the child has used prescribed medicine for the condition during the past 12 months.

Chronically ill children with special needs were defined as having one or more of the designated conditions, who were unable to engage in usual childhood activities, or experienced pain or discomfort often or all of the time. In addition, based on questions in the main questionnaire, children with one or more of the chronic conditions were considered to have special needs, including those who reported that due to illness they were unable to perform or were limited in the kind or amount of their major activities (defined as play for children under 5 years of age and going to school for those aged 5 to 17).

Table 5. Number and Percent of Chronically Ill Children and Those with Special Needs by Condition: 1988

Condition	Children with condition		Children with condition who have special needs	
	Number in thousands	Percent	Number in thousands	Percent
Frequent or repeated ear infections	5,735	9.0	3,580	63.5
Digestive allergies	1,593	2.5	512	32.3
Frequent diarrhea or bowel trouble	1,282	2.0	630	50.4
Diabetes	64	0.1	32	50.6
Sickle cell anemia	74	0.1	12	17.2
Anemia	703	1.1	179	25.5
Asthma	2,700	4.2	1,739	65.3
Hay fever or respiratory allergies	5,830	9.2	2,300	40.4
Epilepsy or seizures	422	0.7	269	65.5
Frequent or severe headaches	1,796	2.8	1,280	76.3
Arthritis or other joint problems	290	0.5	178	62.1
Other musculoskeletal impairments	630	1.0	358	59.0
Cerebral palsy	112	0.2	100	90.9
Heart disease	958	1.5	298	32.2
Other conditions	1,455	2.3	812	57.9

Table source: Aday (1992), Table 1.

Data source: National Health Interview Survey on Child Health

Table 6. Number and Percent of Chronically Ill Children with Special Needs by Selected Characteristics: 1988

HIGHLIGHTS

- About 9.6 million (15.2%) of children under 18 years of age were estimated to have special needs. Special needs is defined as those for whom the condition caused problems, such as missing school, staying in bed or other limiting their usual activities, or experiencing pain or discomfort often or all of the time in the last year.

- Prevalence of chronically ill children with special needs was higher for boys (15.8%) than for girls (14.5%).

- The rates were also higher among nonminority than among minority children: 16% for white children compared with 12.4% for black children and 15.6% for non-Hispanic children compared with 12.1% for Hispanic children.

- The prevalence rates for children who lived neither with both biological parents nor their biological mother (10.8%), as well as for children who had neither private insurance nor Medicaid coverage (13.1%), were lower than the rates for their counterparts.

EXPLANATORY NOTES

The lower prevalence rates reported for uninsured children, minority children, and children not living with either biological parents may be due to underreporting and differential nonresponse for children in these categories.

The children represented in this table were identified to have had one or more of a number of childhood conditions in the NHIS-CH condition record. Respondents were asked whether the child had ever had the condition; if so, whether they had it in the last 12 months. For selected conditions, those who had experienced it in the last year were asked whether it had lasted at least 3 months.

For conditions that met these criteria, the respondent was asked whether the child missed any school, stayed in bed, or otherwise limited usual activities. Also asked was how much pain, discomfort, or bother the child has experienced during the past 12 months due to the condition. The respondent was also asked the number of nights, if any, the child has been hospitalized, the number of times a medical professional was consulted about the child's condition, and if the child has used prescribed medicine for the condition during the past 12 months.

Chronically ill children with special needs were defined as having one or more of the designated conditions, who were unable to engage in usual childhood activities, or experienced pain for discomfort often or all of the time. In addition, based on questions in the main questionnaire, children with one or more of the chronic conditions were considered to have special needs, including those who reported that due to illness they were unable to perform or were limited in the kind or amount of their major activities (defined as play for children under 5 years of age and going to school for those aged 5 to 17).

Table 6. Number and Percent of Chronically Ill Children with Special Needs by Selected Characteristics: 1988

Characteristic	Number of children (in thousands)	Percent of children
All children[1]	9636	15.2
Age		
Under 5 years	2868	15.6
5 - 17 years	6768	15.0
Sex		
Male	5126	15.8
Female	4510	14.5
Race		
White	8199	16.0
Black	1213	12.4
Hispanic origin		
Hispanic	877	12.1
Non-Hispanic	8587	15.6
Family structure		
Biological mother and father	5838	15.0
Biological mother only	3107	17.1
All other	692	10.8
Family income		
Less than $25,000	3773	15.3
$25,000 or more	5121	16.1
Place of residence		
MSA, central city	2745	14.5
MSA, not central city	4468	15.2
Not MSA	2423	15.9
Insurance coverage		
Private insurance	6969	15.7
Medicaid	1006	16.5
Neither	1175	13.1

[1] Numbers for respective groups may not sum to total due to missing values.

Table source: Aday (1992), Table 2.

Data source: National Health Interview Survey on Child Health

Table 7. Conditions Reported as Cause of Disability in Children 0 to 17 Years Old: 1991-92

HIGHLIGHTS

- An estimated 1.44 million children (29.5%) were reported by their parents to have learning disability as the first, second or third condition causing disability. The next most prevalent cause of disability was speech problems (13.1%), followed by mental retardation (6.8%), asthma (6.4%), and mental or emotional problems (6.3%). Another 13.4% had conditions other than the ones identified by the survey.

EXPLANATORY NOTES

These data are from the Survey of Income and Program Participation (SIPP), a panel survey of the economic conditions of people in the United States. It is designed to provide detailed information about income distribution and about federal and state income transfer and service programs. It also provides information for respondents 15 and older about limiting conditions. Disability data for children under age 22 are obtained from their parents.

Parents were shown a card with the condition listed on it and asked: I have recorded that (name) has difficulties with certain activities. Which condition or conditions on this card are responsible for these difficulties? Any other?

Table 7. Conditions Reported as Cause of Disability in Children 0 to 17 Years Old: 1991-92

Condition	Number of times reported as: (Number in thousands)							
	First, second or third condition		First condition		Second condition		Third condition	
	N	%	N	%	N	%	N	%
TOTAL	4858	100.0	3357	100.0	965	100.0	536	100.0
Asthma	311	6.4	281	8.4	18	1.9	12	2.2
Autism	48	1.0	37	1.1	11	1.1	–	–
Blindness or vision problem	144	3.0	95	2.8	41	4.2	8	1.5
Cancer	26	0.5	16	0.5	10	1.0	–	–
Cerebral Palsy	129	2.7	110	3.3	16	1.7	3	0.6
Deafness or serious trouble hearing	116	2.4	74	2.2	35	3.6	7	1.3
Diabetes	14	0.3	14	0.4	–	–	–	–
Drug or alcohol problem or disorder	48	1.0	42	1.3	6	0.6	–	–
Epilepsy or seizure disorder	128	2.6	103	3.1	23	2.4	2	0.4
Hay fever or other respiratory allergies	76	1.6	24	0.7	26	2.7	26	4.9
Head or spinal cord injury	45	0.9	31	0.9	14	1.5	–	–
Heart trouble	44	0.9	22	0.7	18	1.9	4	0.7
Impairment to or deformity of back, side, foot, or leg	121	2.5	89	2.7	27	2.8	5	0.9
Impairment or deformity of finger, hand, or arm	27	0.6	10	0.3	17	1.8	–	–
Learning disability	1435	29.5	1160	34.6	187	19.4	88	16.4
Mental or emotional problem or disorder	305	6.3	175	5.2	108	11.2	22	4.1
Mental retardation	331	6.8	201	6.0	70	7.3	60	11.2
Missing legs, feet, toes, arms, hands, or fingers	70	1.4	66	2.0	4	0.4	–	–
Paralysis of any kind	73	1.5	41	1.2	15	1.6	17	3.2
Speech problems	634	13.1	359	10.7	141	14.6	134	25.0
Tonsillitis or repeated ear infections	80	1.6	15	0.4	32	3.3	33	6.2
Other	653	13.4	392	11.7	146	15.1	115	21.5

– Represents zero.

Table source: McNeil (1993), Table 36.

Data source: Survey of Income and Program Participation, 1991-92

Table 8. Age at which Youth were Reported by Parents as First Experiencing Difficulty with Disabilities: 1987

HIGHLIGHTS

- Most youth were reported to have experienced disability-related problems well before entering secondary school. Overall, 16.5% of youth were reported to have begun having disability-related problems before they were one year old. Another 10% had such problems before reaching school age.

- The largest percentage of youth were reported to have begun experiencing trouble with a disability (65%) during the elementary school years (between the ages of 5 and 12). In all, more than 9 in 10 youth reportedly began having disability-related difficulties before they were 13 years old.

- The typical age at which youth began having trouble with their disabilities varied for youth in different disability categories. For example, youth with sensory impairments were most likely to be reported as having experienced difficulty before age 1. According to parent reports, more than two-thirds of youth who were deaf (67%), visually impaired (69%), or deaf/blind (88%) experienced difficulty at that early age. In contrast, students classified as learning disabled (50%), emotionally disturbed (41%), or speech impaired (38%) were most likely to have begun experiencing difficulties in the early elementary grades.

- Only for youth who were emotionally disturbed or other health impaired were more than 10% reported to have begun having difficulty after age 12 (16% and 14%, respectively).

EXPLANATORY NOTES

The data in this table are from the National Longitudinal Transition Study of Special Education Students (NLTS) which was designed to report on the experiences of youth with disabilities in the areas of education, employment, and personal independence. The survey included more than 8,000 youth nationwide who were students in special education in secondary school in the 1985-86 school year. Data were collected 1987, 1989, and 1990.

The data for this table come from the NLTS parent interviews. The NLTS data reflect only parent perceptions of their children's disability, and some inaccuracy of memory is assumed. However, this dimension of disability is of interest because it provides an estimate of the relative length of time for which youth had been affected by their disabilities.

Table 8. Age at which Youth were Reported by Parents as First Experiencing Difficulty with Disabilities: 1987

Disability Category	Percentage Reported as First Experiencing Difficulty					
	Before Age 1	Ages 1-4	Ages 5-8	Ages 9-12	Ages 13+	N
All conditions	16.5	10.4	42.7	22.4	8.0	6454
Learning disabled	6.6	7.3	50.3	28.0	7.8	852
Emotionally disturbed	8.9	11.3	41.4	22.1	16.2	546
Speech impaired	17.1	15.2	38.0	21.4	8.3	420
Mentally retarded	32.6	14.7	34.3	13.0	5.5	832
Visually impaired	68.9	10.8	11.5	5.2	3.6	719
Hard of hearing	45.2	24.5	21.3	7.5	1.5	653
Deaf	67.1	26.0	5.7	.8	.4	768
Orthopedically impaired	57.6	11.1	10.8	10.5	9.9	621
Other health impaired	29.3	14.8	20.2	21.9	13.7	376
Multiply handicapped	59.1	18.5	13.2	7.1	2.1	588
Deaf/blind	88.4	6.4	1.5	3.7	0.0	79

Table source: Marder & Cox (1991), Table 2-9.

Data source: National Longitudinal Transition Study of Special Education Students

Table 9. Socioeconomic Characteristics of Youth with Disabilities and Youth in the General Population: 1985-86

HIGHLIGHTS

- The head of household's educational attainment was significantly lower for youth with disabilities than for youth in general. Parents or guardians who had not completed high school were heads of household of 41% of youth with disabilities, compared with 22% of all youth aged 12 to 17. Only 23% of the heads of household of youth with disabilities had at least some college, and only 9% had completed a 4-year degree program. Comparable figures for the general population of youth were 39% and 21%, respectively.

- Typical household income for youth with disabilities was considerably lower than for youth in general. Annual household income was less than $12,000 for 35% of youth with disabilities, and less than $25,000 for 68%. Comparable figures for the general population of youth from 12 to 17 years of age indicate that 18% were in households with incomes of less than $12,500, and 39% were in households with incomes of less than $25,000.

- Although 36% of the general population of youth were in households with incomes of $40,000 or more, only 15% of youth with disabilities were in households with incomes of $38,000 or more.

- About half of all youth with disabilities lived in households that were receiving benefits from at least one public source in 1987. The benefits most often received were Food Stamps (24%) and Medicaid or other state-supported health benefits (22%).

EXPLANATORY NOTES

Data presented for youth in the general population are only approximately comparable to the NLTS data. Boundaries for income categories by the NLTS differ slightly from those used by the U.S. Census ($12,000 versus $12,500 and $38,000 versus $40,000). However, these discrepancies are not responsible for the differences observed between the two populations because they would tend to bias the result of a comparison in the direction opposite to that actually observed.

Table 9. Socioeconomic Characteristics of Youth with Disabilities and Youth in the General Population: 1985-86

Socioeconomic Characteristics	Percentage of Youth with Disabilities	Percentage of Youth in the General Population†
Education of household head	N = 6650	
Less than high school	41.0	22.3
High school graduate	36.0	38.8
Some college/2-year degree	14.0	17.8
4 year degree or more	8.9	21.1
Annual household income	N = 6092	
Under $12,000	34.8	18.2
$12,000 to $24,999	33.5	20.6
$25,000 to $37,999	16.2	25.4
$38,000 or more	15.4	35.8
Receiving public benefits	N=6631	
Food stamps	23.7	12.9§
Medicaid or similar coverage	21.6	12.6§
Supplemental Security Income (SSI)	14.4	
AFDC	12.5	12.6‡
Public assistance	10.8	
Social Security Disability Insurance (SSDI)	9.6	
Social Security Survivors Benefits	8.1	
Unemployment insurance	7.3	
Other benefits	4.3	
Receiving one or more benefits	49.9	

† U.S. Bureau of the Census (1988). Marital status and living arrangements: March 1987. (CPR P-25, NO. 1024). Washington, DC: U.S. Government Printing Office, Table 9. Data refer to youth aged 12 to 17 and living with at least one parent in March 1987.

§U.S. Department of Education (1988). Youth indicators 1988. Washington, DC: U.S. Government Printing Office, p. 34. Percentage of households with youth aged 0 to 18 in 1985.

‡U.S. Department of Education (1988), Youth indicators 1988. Washington, DC: U.S. Government Printing Office, p. 32. Percent of youth aged 0 to 17 in 1985.

Table source: Marder & Cox (1991), Table 2-16.

Data source: National Longitudinal Transition Study of Special Education Students

Table 10. Demographic and Household Characteristics of Youth with Disabilities by Disability Category: 1987

HIGHLIGHTS

- Of the special education students who were ages 13 to 21 during the 1985-86 school year, 38.1% were 17 or 18 years old, with the average age of 17.5 years.

- Boys comprised 68.5% of all youth with disabilities. Three-fourths of youth who were learning disabled (73.4%) and emotionally disturbed (76.4%) were male.

- Overall, most youth in special education were white (65%), with black students comprising 24.2% and Hispanic students 8.1% of special education students who were ages 13 to 21 during the 1985-86 school year.

- A little over one-third (36.8%) of the students lived with a single parent and 5.5% lived in a household with neither natural parent. One-fifth (19.1%) lived in a household with other disabled children, and 11% in households where the head of the household was disabled.

EXPLANATORY NOTES

The data presented here were collected in 1987 for a sample of more than 8,000 youth who represent the national population of secondary special education students who were ages 13 to 21 in the 1985-86 school year. The data were collected in the first phase of the National Longitudinal Transition Study of Special Education Students (NLTS). Additional data were collected in 1990.

Percentages and means are weighted to represent the national population of youth with disabilities and youth in each disability category.

Table 10. Demographic and Household Characteristics of Youth with Disabilities by Disability Category: 1987

		Primary Disability Category										
Characteristics of Youth	Total	Learning Disabled	Emotionally Disturbed	Speech Impaired	Mentally Retarded	Visually Impaired	Hard of Hearing	Deaf	Orthoped-ically Impaired	Other Health Impaired	Multiply Disabled	Deaf/ Blind
Percentage of youth												
15 or 16 years old	33.1	34.8	36.9	48.7	26.6	29.4	30.9	21.9	25.1	29.2	30.5	9.9
17 or 18 years old	38.1	40.7	39.0	33.1	33.5	37.1	36.1	29.4	35.3	40.5	27.7	20.5
19 to 21 years old	26.5	24.0	22.7	17.7	34.2	28.8	28.6	38.9	36.0	27.4	29.2	21.9
More than 21 years old	2.3	0.6	1.4	0.5	5.7	4.7	4.4	9.8	3.6	3.0	12.6	47.7
Number of respondents	8408	1191	779	588	1204	875	770	918	764	475	744	100
Average age	17.5	17.3	17.3	16.9	18.1	17.8	17.8	18.5	18.0	17.6	18.3	20.3
Number of respondents	8408	1191	779	588	1204	875	770	918	764	475	744	100
Percentage who were male	68.5	73.4	76.4	59.5	58.0	55.6	52.0	54.5	54.2	56.0	65.4	49.5
Number of respondents	8392	1189	777	585	1201	872	769	917	764	475	744	99
Percentage who were:												
Black, not Hispanic	24.2	21.6	25.1	28.0	31.0	25.9	18.7	24.5	19.0	20.3	19.1	25.0
White, not Hispanic	65.0	67.2	67.1	54.2	61.0	63.6	63.4	62.7	63.1	54.2	65.6	67.0
Hispanic	8.1	8.4	6.0	14.2	5.6	8.1	13.6	9.6	15.1	22.5	12.1	5.8
American Indian/Alaskan	1.2	1.2	0.9	0.8	1.4	0.4	0.5	0.4	0.5	1.0	0.2	0.0
Asian/Pacific Islander	0.7	0.6	0.1	2.4	0.4	1.5	2.2	2.1	1.8	1.5	2.1	1.0
Other	0.8	1.0	0.7	0.3	0.6	0.5	1.5	0.7	0.5	0.5	0.9	1.2
Number of respondents	7141	994	644	490	936	755	685	797	681	437	636	86
Percentage in households with:												
A single parent	36.8	34.3	44.3	42.2	38.6	36.8	32.0	38.9	38.5	43.2	36.9	30.8
Neither natural parent	5.5	5.2	6.0	6.4	6.0	5.2	4.5	7.0	7.2	4.5	7.4	8.3
Other disabled children	19.1	18.4	19.7	19.0	21.6	17.2	15.6	13.1	12.2	19.7	18.7	7.0
Disabled head of household	11.0	10.1	12.3	13.0	12.9	12.2	11.9	10.1	7.9	10.4	9.3	9.3
Number of respondents	6385	894	570	427	813	699	638	746	607	388	527	76

Table source: Valdes, Williamson, & Wagner (1990), Tables 1A and 2A.
Data source: National Longitudinal Transition Study of Special Education Students

Table 11. Percent of Children 17 Years of Age and Under Who Ever Had a Delay in Growth or Development, by Age and Selected Characteristics: 1988

HIGHLIGHTS

- The overall proportion of children with developmental delays was 4%. By age groups, it was 4.3% for 2 years of age and under, 4.4% at ages 3-5, 4.1% at ages 6-11 years, and 3.6% for adolescents aged 12-17.

- Differences between boys and girls were relatively slight for developmental delays, 4.2% of boys versus 3.8% of girls were reported to have had delays in growth or development. Some age groups show minimal differences or reversals.

- Black parents were less likely than white parents to report that their children had developmental delays or emotional problems and about equally likely to report learning disabilities. Hispanic parents also reported slightly fewer developmental problems in their children than did non-Hispanic parents. Thus the overall prevalence of developmental delays was 2.1% among black and 4.4% among white children; 3.4% among Hispanic and 4.2% among non-Hispanic children.

- Differences across parental education and income groups in the proportion of children who had delays in growth or development were relatively small and mostly not statistically significant. Among family income groups, only the contrast between the lowest category (less than $10,000) and the highest ($40,000) was statistically reliable. Of children in the former group, 5.4% had developmental delays, but of those in the latter group, 3.9% had delays.

- The prevalence of developmental delays showed little significant variation across family types. Prevalence was 3.8% among children from mother-father families, 4.5% among children in mother-only families, 3.7% in mother-stepfather families, and 4.8% in all other family situations (children living with fathers only or father and stepmother, with grandparents or other relatives, or in adoptive or foster families).

EXPLANATORY NOTES

The source of data for this table is the 1988 National Health Interview Survey of Child Health. Parents of children of all ages were asked whether their child had ever had a delay in growth or development. It was expected that respondents who answered yes to this question would consist partly of parents whose children had limited or temporary deficits in growth or development associated with premature birth or an early illness or injury, and partly of parents whose children had severe and long-lasting deficits, such as those produced by Down syndrome or other chromosomal abnormalities, hereditary factors, prenatal infection, birth injury, or childhood diseases.

Interviewers did not ask about mental retardation because the term is seen as limiting or stigmatizing by parents of children with developmental disorders.

Table 11. Percent of Children 17 Years of Age and Under Who Ever Had a Delay in Growth or Development, by Age and Selected Characteristics: 1988

Characteristic	All ages 17 and under	2 years and under	3 - 5 years	6 - 11 years	12 - 17 years
All children[1]	4.0	4.3	4.4	4.1	3.6
Sex					
Male	4.2	4.0	4.6	4.0	4.4
Female	3.8	4.6	4.2	4.2	2.7
Race					
White	4.4	4.5	4.7	4.5	4.0
Black	2.1	2.5	1.4	2.3	2.0
Hispanic origin					
Hispanic	3.4	1.8	4.2	3.7	3.7
Non-Hispanic	4.2	4.7	4.5	4.2	3.6
Family income					
Less than $10,000	5.4	6.9	5.8	5.4	3.8
$10,000 - $24,999	4.0	4.4	4.1	3.3	4.4
$25,000 - $39,999	4.0	2.6	6.1	4.5	3.3
$40,000 or more	3.9	5.0	2.5	4.3	3.6
Place of residence					
MSA	3.8	3.7	3.5	4.2	3.6
Central city	3.1	2.8	3.1	3.6	2.9
Not central city	4.2	4.4	3.8	4.6	4.0
Not MSA	4.7	6.1	7.1	3.7	3.8
Assessed health status					
Excellent, very good, or good	3.7	3.7	3.7	3.8	3.5
Fair or poor	15.2	21.0	24.5	14.0	8.5
Mother's education					
Less than 12 years	3.3	4.2	4.3	3.2	2.6
12 years	4.2	4.8	5.4	3.8	3.8
More than 12 years	4.2	3.8	3.4	5.0	4.2
Family structure					
Biological mother and father	3.8	3.4	4.4	3.6	3.9
Biological mother and stepfather	3.7	10.1	3.6	4.5	2.6
Biological mother only[2]	4.5	5.5	3.8	4.6	4.2
All other	4.8	9.5	6.5	5.4	2.6

[1] Includes other races and unknown sociodemographic and health characteristics
[2] Includes families in which the mother lived with the child's grandmother or other adult relative

Table source: Zill & Schoenborn, 1990, Table 1.
Data source: National Health Interview Survey of Child Health

Table 12. Percent of Children 3-17 Years of Age Who Ever Had a Learning Disability, by Age and Selected Characteristics: 1988

HIGHLIGHTS

- According to parents, 3.4 million (6.5%) of children ages 3-17 have had a learning disability. Most learning disabilities are not apparent until the child enters school and begins to read, write, and calculate. The proportion of children with learning disabilities rose from 1.6% at ages 3-5 to 6.8% in the elementary school ages, 6-11 years. There was a further increase, to 8.8%, in the junior and high school ages, 12-17 years.

- The rate of learning disabilities was almost twice as high among boys as among girls, 8.6% versus 4.4% for ages 3-17 years. By adolescence, more than twice as many boys as girls (12.1% versus 5.2%) were described as having learning disabilities.

- The prevalence of learning problems decreased with increasing years of mother's education. The proportion of children reported to have learning disabilities was 8.7% for children of mothers with less than 12 years of schooling, 6.8% for those whose mothers had 12 years of education, and 4.9% for children whose mothers had more than 12 years of schooling. Similar patterns were observed in all age groups.

- The prevalence of learning problems decreased with increasing income. The prevalence was 8.4% among children from families with incomes less than $10,000 per year and decreased as income rose, reaching 5.8% among children in families with incomes of $40,000 or more. Except for a few nonsignificant fluctuations, similar patterns were found for all age groups.

- Black parents were as likely as white parents to report learning disabilities. Hispanic parents reported slightly fewer problems in their children than did non-Hispanic parents. The proportion of children ages 3-17 years with learning disabilities was 6.2% among black and 6.7% among white children; 5.8% among Hispanic and 6.6% among non-Hispanic children.

- There was significant variation across family types in the prevalence of learning disability with children in disrupted or reconstituted families showing higher rates of learning problems than those in mother-father families. Children in mother-stepfather families showed slightly higher rates of learning problems than those in mother-only families, but this may be attributable to the fact that black and Hispanic persons, with their lower rates of problem reporting, were overrepresented in the mother-only group but not in the mother-stepfather group. The prevalence of learning disabilities was 5.5% among children in mother-father families, 7.5% in mother-only families, 9.1% in mother-stepfather families, and 8.3% in other family situations.

EXPLANATORY NOTES

The source of data for this table is the 1988 National Health Interview Survey of Child Health. Parents of children ages 3 - 17 were asked whether their child had ever had a learning disability. Ideally, this question would be answered yes for children who had exceptional difficulty learning to read, write, or do arithmetic but whose learning problems did not stem from mental retardation, impairment of sight or hearing, emotional problems, or lack of educational opportunities. It is likely, however, that parents applied the term not only to children with specific incapacities but also to some children with deficits in general intelligence or behavioral problems that interfered with their learning.

Table 12. Percent of Children 3-17 Years of Age Who Ever Had a Learning Disability, by Age and Selected Characteristics: 1988

Characteristic	All ages 17 and under	3 - 5 years	6 - 11 years	12 - 17 years
All children[1]	6.5	1.6	6.8	8.8
Sex				
Male	8.6	1.7	8.4	12.1
Female	4.4	1.6	5.1	5.2
Race				
White	6.7	1.6	7.0	9.2
Black	6.2	2.0	6.6	7.8
Hispanic origin				
Hispanic	5.8	2.1	6.8	6.7
Non-Hispanic	6.6	1.6	6.8	8.9
Family income				
Less than $10,000	8.4	3.8	9.1	10.3
$10,000 - $24,999	7.2	1.4	7.3	10.6
$25,000 - $39,999	6.2	1.7	5.5	9.4
$40,000 or more	5.8	1.2	6.5	7.2
Place of residence				
MSA	6.5	1.6	7.1	8.6
Central city	5.9	1.8	6.5	7.6
Not central city	6.9	1.5	7.4	9.1
Not MSA	6.5	1.8	5.9	9.5
Assessed health status				
Excellent, very good, or good	6.3	1.4	6.5	8.6
Fair or poor	15.1	9.3	17.7	15.6
Mother's education				
Less than 12 years	8.7	2.8	8.0	11.7
12 years	6.8	1.9	7.5	8.5
More than 12 years	4.9	0.9	5.2	7.1
Family structure				
Biological mother and father	5.5	1.2	5.7	8.2
Biological mother and stepfather	9.1	3.1	9.2	10.1
Biological mother only[2]	7.5	3.0	7.2	9.8
All other	8.3	1.1	10.6	8.6

[1] Includes other races and unknown sociodemographic and health characteristics

[2] Includes families in which the mother lived with the child's grandmother or other adult relative

Table source: Zill & Schoenborn (1990), Table 2.

Data source: National Health Interview Survey of Child Health

Table 13. Percent of Children 3-17 Years of Age Who Ever Had an Emotional or Behavioral Problem That Lasted 3 Months or More or Required Psychological Help, by Age and Selected Characteristics: 1988

HIGHLIGHTS

- According to their parents, 13.4% of children ages 3-17 years, or 7 million, have had an emotional or behavioral problem that lasted 3 months or more or required psychological treatment.

- The proportion of children who had ever had an emotional or behavioral problem rose from 5.3% at ages 3-5 years, to 12.7% at ages 6-11 years, to 18.5% at ages 12-17 years.

- The overall prevalence of emotional and behavioral problems was 36% higher among boys: 15.4% versus 11.3% for girls. Sex differences were most pronounced for children of elementary school age (6-11 years), with 15.6% of boys versus 9.8% of girls in this age range experiencing such problems.

- The prevalence of childhood emotional and behavioral problems showed significant variation across family income groups, with children from less advantaged backgrounds exhibiting a greater proportion of such problems. The prevalence declined from 15.8% among children from families with incomes less than $10,000 per year to 12.8% among those with family incomes of $40,000 or more. Income-related differences were more pronounced among elementary school children and adolescents than among preschoolers.

- Black parents were less likely than white parents to report that their children had emotional problems. The proportion of children ages 3-17 years reported to have had emotional or behavioral problems was 10.3% among black and 14.2% among white children; 12% among Hispanic and 13.6% among non-Hispanic children.

- Frequency of emotional and behavioral problems showed the greatest variation across family types, with children in single-parent families and stepfamilies showing higher problem rates than those in mother-father families. Children in other types of families also showed elevated rates. The prevalence of emotional and behavioral problems was 8.3% in mother-father families, 19.1% in mother-only families, 23.6% in mother-stepfather families, and 22.2% in other family situations. The frequency of problems among children in mother-only families may be understated because of the large proportions of black and Hispanic persons in this group.

EXPLANATORY NOTES

The source of data for this table is the 1988 National Health Interview Survey of Child Health. Parents of children ages 3 -17 years were asked whether their child had ever had an emotional or behavioral problem that lasted 3 months or more. This question was meant to identify children with common psychological syndromes such as aggressive or antisocial conduct, attention-deficit hyperactivity disorder, phobias and anxiety disorders, childhood depression, and adjustment reactions to traumatic events such as parental divorce. More severe conditions such as autism and schizophrenia would also be picked up, but in very small numbers given the rarity of these conditions.

Table 13. Percent of Children 3-17 Years of Age Who Ever Had an Emotional or Behavioral Problem That Lasted 3 Months or More or Required Psychological Help, by Age and Selected Characteristics: 1988

Characteristic	All ages 17 and under	3 - 5 years	6 - 11 years	12 - 17 years
All children[1]	13.4	5.3	12.7	18.5
Sex				
Male	15.4	6.1	15.6	20.4
Female	11.3	4.5	9.8	16.5
Race				
White	14.2	5.6	13.6	19.5
Black	10.3	2.4	9.2	15.1
Hispanic origin				
Hispanic	12.0	4.5	13.4	14.8
Non-Hispanic	13.6	5.4	12.7	18.9
Family income				
Less than $10,000	15.8	4.7	16.2	22.5
$10,000 - $24,999	14.5	6.0	15.0	19.3
$25,000 - $39,999	13.4	5.9	11.5	19.6
$40,000 or more	12.8	4.8	11.4	17.6
Place of residence				
MSA	13.7	5.2	12.9	19.1
Central city	13.6	4.7	13.1	19.1
Not central city	13.8	5.5	12.8	19.1
Not MSA	12.4	5.5	12.0	16.5
Assessed health status				
Excellent, very good, or good	13.1	5.0	12.5	18.1
Fair or poor	23.3	8.4	20.4	31.8
Mother's education				
Less than 12 years	13.6	5.2	12.3	18.5
12 years	12.5	6.2	11.8	16.7
More than 12 years	13.7	4.2	13.3	20.1
Family structure				
Biological mother and father	8.3	4.0	8.0	11.6
Biological mother and stepfather	23.6	12.0	19.6	29.1
Biological mother only[2]	19.1	6.6	18.9	25.5
All other	22.2	10.0	22.6	25.8

[1] Includes other races and unknown sociodemographic and health characteristics
[2] Includes families in which the mother lived with the child's grandmother or other adult relative

Table source: Zill & Schoenborn, (1990), Table 3.

Data source: National Health Interview Survey of Child Health

Table 14. Percent of Children 3-17 Years of Age Who Ever Had a Delay in Growth or Development, a Learning Disability, or an Emotional or Behavioral Problem That Lasted 3 Months or More or Required Psychological Help, by Age and Selected Characteristics: 1988

HIGHLIGHTS

- The combined lifetime prevalence of developmental, learning, and emotional problems increased substantially with age, more than doubling from ages 3-5 years (9.5%) to 12-17 years (25.2%). One teenager in four was reported to have had a developmental delay, learning disability, or emotional or behavioral problem.

- For all three types of problems combined, the prevalence for boys exceeded that for girls by 43%: 22.9% compared with 16%. Among adolescents (ages 12-17 years), the male rate exceeded the female rate by 40%: 29.2% versus 20.8%. Nearly 3 teenage boys in 10 had had a developmental delay, learning disability, or emotional or behavioral problem.

- Significant variation by family income, but not by parental education, was found when all three types of conditions were combined. The proportion of children ages 3-17 years with one or more of these problems fell from 22.8% among children in families with incomes below $10,000 to 18.6% among those with family incomes of $40,000 or more. The proportion was 20.3% among children of mothers with less than 12 years of education and 19.3% among those whose mothers had more than 12 years of schooling.

- Children in disrupted families were nearly twice as likely as those in mother-father families to have had a developmental, learning, or behavioral problem. The prevalence for children ages 3-17 years was 14.6% in mother-father families, 24.8% in mother-only families, 29.6% in mother-stepfather families, and 28.2% in other family types.

EXPLANATORY NOTES

The source of data for this table is the 1988 National Health Interview Survey of Child Health. Parents of children of all ages were asked whether their child had ever had a delay in growth or development. Parents of children ages 3-17 were asked if their child had ever had a learning disability, or an emotional or behavioral problem that lasted 3 months or more.

Table 14. Percent of Children 3-17 Years of Age Who Ever Had a Delay in Growth or Development, a Learning Disability, or an Emotional or Behavioral Problem That Lasted 3 Months or More or Required Psychological Help, by Age and Selected Characteristics: 1988

Characteristic	All ages 17 and under	3 - 5 years	6 - 11 years	12 - 17 years
All children[1]	19.5	9.5	19.1	25.2
Sex				
Male	22.9	10.5	22.8	29.2
Female	16.0	8.5	15.4	20.8
Race				
White	20.7	10.0	20.3	26.7
Black	14.9	5.0	14.8	19.5
Hispanic origin				
Hispanic	17.2	8.5	19.6	19.2
Non-Hispanic	19.9	9.7	19.1	25.8
Family income				
Less than $10,000	22.8	11.5	23.8	28.6
$10,000 - $24,999	21.0	10.1	21.3	27.3
$25,000 - $39,999	19.5	11.3	17.6	26.0
$40,000 or more	18.6	6.8	18.0	24.1
Place of residence				
MSA	19.6	8.5	19.5	25.4
Central city	18.7	8.0	19.2	24.1
Not central city	20.1	8.9	19.6	26.1
Not MSA	19.4	12.3	17.9	24.6
Assessed health status				
Excellent, very good, or good	19.1	8.9	18.7	24.8
Fair or poor	35.3	25.7	35.7	39.3
Mother's education				
Less than 12 years	20.3	10.2	18.4	26.2
12 years	19.0	11.2	18.8	23.2
More than 12 years	19.3	7.3	19.4	26.3
Family structure				
Biological mother and father	14.6	8.1	14.4	19.2
Biological mother and stepfather	29.6	14.4	27.0	34.5
Biological mother only[2]	24.8	11.7	24.5	31.4
All other	28.2	13.5	29.7	31.4

[1] Includes other races and unknown sociodemographic and health characteristics

[2] Includes families in which the mother lived with the child's grandmother or other adult relative

Table source: Zill & Schoenborn (1990), Table 4.

Data source: National Health Interview Survey of Child Health

Table 15. Percent Distribution and Cumulative Distribution of Children 3-17 Years of Age with Developmental, Learning, and Emotional Problems by Age at Which Condition was First Noticed, According to Type of Problem: 1988

HIGHLIGHTS

- When parents were asked the child's age at the time they first noticed developmental delays, 25% of those who reported delays said they had been apparent since birth. Forty-five percent of delays were noticed before the child's first birthday. The median age at which delays in growth or development were noticed was 1 year, 2 months.

- Only 6% of parents who reported learning problems said the problem had been apparent since birth or before the child's first birthday. One-quarter of the learning disabilities became apparent during the nursery school or kindergarten years (ages 3-5 years), and another 45% were first noticed in early elementary school (ages 6-8 years). Learning disabilities were not picked up until late elementary or secondary school for 16% of the children. The median age at which learning disabilities were first noticed was 6 years, 7 months.

- Of parents who reported that their children had emotional or behavioral problems that had lasted 3 months or more, only 5% said it was noticed before the child's first birthday. Less than 15% of the emotional problems were noticed during the first 3 years of life. One-quarter emerged during the preschool years (ages 3-5) and another quarter during the early elementary years (ages 6-8). The rate of problem emergence tapered off in the late elementary years, with 15% or the conditions appearing during ages 9-11 years. During the adolescent years (ages 12-17), 22% of problems became evident. The median age at which persistent emotional behavioral problems were noticed was 7 years, 2 months.

EXPLANATORY NOTES

The source of data for this table is the 1988 National Health Interview Survey of Child Health. Parents of children of all ages were asked whether their child had ever had a delay in growth or development. Parents of children ages 3-17 were asked if their child had ever had a learning disability, or an emotional or behavioral problem that lasted 3 months or more. Parents who reported any of these conditions were asked when each condition was first noticed.

Table 15. Percent Distribution and Cumulative Distribution of Children 3-17 Years of Age with Developmental, Learning, and Emotional Problems by Age at Which Condition was First Noticed, According to Type of Problem: 1988

Age at which condition was first noticed	Delays in growth or development[1]		Learning disabilities		Emotional or behavioral problems[2]	
	Percent distribution	Cumulative percent distribution	Percent distribution	Cumulative percent distribution	Percent distribution	Cumulative percent distribution
At birth	25	25	4	4	3	3
Before 1 year	20	45	2	6	2	5
1 - 2 years	26	71	8	14	9	14
3 - 5 years	12	83	25	39	25	39
6 - 8 years	9	92	45	84	24	63
9 - 11 years	5	97	11	95	15	78
12- 17 years	3	100	5	100	22	100

[1] Ages 0 - 17 years

[2] Question about age when noticed was asked only of those who reported an emotional or behavioral problem that lasted 3 months or longer.

Table source: Zill & Schoenborn (1990), Table 6.

Data source: National Health Interview Survey of Child Health

Table 15a. Selected Statistics on Children 3-17 Years of Age with Developmental, Learning, and Emotional Problems, by Type of Problem: 1988

Item	Delays in growth or development[1]	Learning disabilities	Emotional or behavioral problems[2]
Median age at first notice	1 year 2 months	6 years 7 months	7 years 2 months
Unweighted N	630	862	833
Population estimate	2,542,800	3,393,600	3,184,700

[1] Ages 0-17 years.

[2] These statistics include only those who were reported to have had an emotional or behavioral problem that lasted 3 months or longer.

Table source: Zill & Schoenborn (1990), Table 7.

Data source: National Health Interview Survey of Child Health

Table 16. Disability Status of Children 0 to 17 Years Old, By Sex, Race, and Hispanic Origin: 1991-92

HIGHLIGHTS

- The disability rate among children 0 to 2 years old was 2.2%. The proportion with a limitation in usual kind of activity was 1.3%, and 1.6% had received therapy or services for developmental needs (the latter figure is not statistically different from either of the two preceding figures). The proportion identified as having a severe disability (a limitation caused by autism, cerebral palsy, or mental retardation) was 0.4%.

- The disability rate among children 3 to 5 years was 5.2%. The proportion with a limitation in usual kind of activity was 2.6%, and 4.3% had received therapy or services for developmental needs (the latter figure is not statistically different from the overall figure of 5.2%). The proportion identified as limited in their ability to walk, run or use stairs was 1.3%. The proportion with a severe disability was 0.7%, not statistically different from the rate for children 0 to 2 years old.

- Children 6 to 14 years of age had a disability rate of 6.3%. The proportion who were limited in their ability to do regular school work was 5.4%, and 1.6% were limited in their ability to walk, run, or use stairs. (This latter figure is not statistically different from the comparable figure for children 3 to 5 years old). The proportion with a severe disability was 1.3%.

- The overall disability rate among persons 15 to 17 years of age was 9.3%. The proportion identified as having a limitation in their ability to do regular school work was 4.4%.

EXPLANATORY NOTES

These data are from the Survey of Income and Program Participation (SIPP). Questions about the disability status of children were asked of parents or guardians of children under the age of 22.

Questions about any limitations at all in the usual kind of activities done by most children their age and whether the child received therapy or diagnostic services designed to meet their developmental needs were asked about children 0 to 6 years of age.

A question about limitations in their ability to do regular school work was asked about children 6 to 21 years of age, and a question about a long lasting condition that limits their ability to walk, run, or use stairs was asked about children 3 to 14 years of age.

The disability status of youth 15 to 21 years of age was measured by asking the youth about functional limitation, ADL limitations, IADL limitations, and the use of special aids. If the person lived with a parent or guardian, disability status was also measured by a question asked of the parent or guardian concerning the youth's ability to do regular school work.

Table 16. Disability Status of Children 0 to 17 Years Old, By Sex, Race, and Hispanic Origin: 1991-92
(Number in thousands)

Characteristic	Both sexes		Male		Female		White		Black		Hispanic	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Children less than 3 years	11,791	100.0	6,000	100.0	5,791	100.0	9,426	100.0	1,815	100.0	1,437	100.0
With a disability	254	2.2	133	2.2	121	2.1	203	2.2	45	2.5	17	1.2
Limited in usual kinds of activities	149	1.3	72	1.2	76	1.3	119	1.3	27	1.5	10	0.8
Received services for developmental needs	183	1.6	106	1.8	77	1.3	148	1.6	32	1.8	15	1.0
With a severe disability	41	0.4	32	0.5	8	0.1	32	0.3	9	0.5	2	0.2
Children 3 to 5 years	11,511	100.0	5,946	100.0	5,565	100.0	9,136	100.0	1,888	100.0	1,381	100.0
With a disability	597	5.2	370	6.2	228	4.1	498	5.5	80	4.3	35	2.5
Limited in usual kind of activities	294	2.6	184	3.1	110	2.0	229	2.5	52	2.7	18	1.3
Received services for developmental needs	498	4.3	323	5.4	176	3.2	430	4.7	57	3.0	25	1.8
Limited in ability to walk, run, or use stairs	147	1.3	76	1.3	71	1.3	105	1.2	41	2.2	10	0.7
With a severe disability	75	0.7	54	0.9	21	0.4	62	0.7	7	0.4	2	0.2
Children 6 to 14 years	32,766	100.0	16,761	100.0	16,005	100.0	26,143	100.0	5,165	100.0	3,688	100.0
With a disability	2,062	6.3	1,373	8.2	689	4.3	1,702	6.5	302	5.9	151	4.1
Limited in ability to do regular school work	1,764	5.4	1,197	7.1	567	3.5	1,452	5.6	260	5.0	128	3.5
Limited in ability to walk, run, or use stairs	524	1.6	301	1.8	223	1.4	421	1.6	88	1.7	39	1.1
With a severe disability	412	1.3	250	1.5	163	1.0	357	1.4	44	0.8	22	0.6
Children 15 to 17 years	10,067	100.0	5,172	100.0	4,895	100.0	7,886	100.0	1,700	100.0	1,230	100.0
With a disability	933	9.3	558	10.8	374	7.7	702	8.9	184	10.9	104	8.5
Limited in ability to do regular school work	438	4.4	321	6.2	116	2.4	334	4.2	88	5.2	36	2.9
With a severe disability	309	3.1	159	3.1	150	3.1	207	2.6	94	5.5	28	2.3

Table source: McNeil (1993), Tables 34 and 35.

Data source: Survey of Income and Program Participation, 1991-92

Table 17. Number and Percent of Children Under Age 18 by Degree of Activity Limitation Due to Chronic Conditions, by Sex, Race, and Family Income: 1991

HIGHLIGHTS

- There are an estimated 3.8 million (5.8%) children under age 18 with some degree of activity limitation. Of these children, 2.8 million (4.2%) are limited in their major activity and 1 million (1.6%) are limited, but not in a major activity. Of the 2.8 million limited in their major activity, 326,000 (.5%) are unable to carry on major activity and 2.4 million (3.7%) are limited in amount or kind of major activity.

EXPLANATORY NOTES

Limitation of activity refers to long-term reduction in activity resulting from chronic disease or impairment. The NHIS measure of limitation of activity permits differentiation among (a) persons unable to carry on their usual activity; (b) persons limited in the amount or kind of their usual activity; (c) persons limited but not in their usual activity; and (d) persons not limited.

The category of persons limited in their major activity includes those in the first two groups, that is, those unable to carry on the usual activity and those limited in the amount or kind of usual activity for their age group. For children, the usual activity is play for children under age 5 and going to school for children aged 5-17.

Persons limited, but not in their major activity, include persons restricted in other activities such as civic, church, or recreational activities.

Table 17. Number and Percent of Children Under Age 18 by Degree of Activity Limitation Due to Chronic Conditions, by Sex, Race, and Family Income: 1991

Characteristic	All persons under 18 years (in thousands)	Degree of activity limitation											
		With no activity limitation		With activity limitation		With limitation in major activity		Unable to carry on major activity		Limited in amount or kind of major activity		Limited, but not in major activity	
		Number in thousands	%	Number in thousands	%	Number in thousands	%	Number in thousands	%	Number in thousands	%	Number in thousands	%
All persons under 18 years	65,521	61,725	94.2	3,796	5.8	2,758	4.2	326	0.5	2,432	3.7	1,037	1.6
Sex													
Male	33,535	31,256	93.2	2,278	6.8	1,690	5.0	170	0.5	1,520	4.5	588	1.8
Female	31,986	30,469	95.3	1,517	4.7	1,068	3.3	156	0.5	912	2.9	449	1.4
Race													
White	52,593	49,595	94.3	2,997	5.7	2,161	4.1	261	0.5	1,900	3.6	836	1.6
Black	10,321	9,622	93.2	699	6.8	534	5.2	49	0.5	485	4.7	165	1.6
Family income													
Under $10,000	6,823	6,134	89.9	689	10.1	522	7.7	59	0.9	464	6.8	166	2.4
$10,000 - $19,999	10,092	9,361	92.8	731	7.2	572	5.7	75	0.7	497	4.9	159	1.6
$20,000 - $34,999	14,610	13,829	94.7	782	5.4	576	3.9	63	0.4	513	3.5	206	1.4
$35,000 or more	24,142	23,010	95.3	1,132	4.7	767	3.2	99	0.4	669	2.8	365	1.5

Table source: Adams & Benson (1992), Tables 67 and 68.

Data source: National Health Interview Survey, 1991

Table 18. Percent of Children with Physical, Emotional, or Mental Condition which Limits Activity, by Ethnicity, Age, and Poverty Status: 1988

HIGHLIGHTS

- At the 1988 survey point, 1.8% of all children had a condition which limited regular school attendance, 2.1% had a condition which limited school work, and 3.2% had a condition which limited play or sports activity.
- These estimates vary only slightly by race/ethnicity or age of child.
- Children in poor families have slightly higher disability rates than children whose families are not poor (2.4% versus 1.5% for school attendance; 2.6% versus 2.2% for school work; and 4.6% versus 2.7% for play or sports).

EXPLANATORY NOTES

These data are from the National Longitudinal Survey of Youth (NLSY). The child health section of the child supplement collects information from the mother every two years on the child's health limitations, accidents and injuries, medical treatment in the last 12 months and health insurance coverage.

The children of the sampled women are representative of American children who have been born to American mothers who were 23 to 31 years of age on January 1, 1988.

Table 18. Percent of Children with Physical, Emotional, or Mental Condition which Limits Activity, by Ethnicity, Age, and Poverty Status: 1988 (Weighted Population Estimates)

Characteristic	Percent Limiting Regular School Attendance[1]		Percent Limiting Regular School Work[1]		Percent Limiting Usual Childhood Activities Such as Play or Sports Participation	
	%	N	%	N	%	N
Total	1.8	3603	2.1	3599	3.2	6231
Hispanic	2.2	649	2.1	648	4.7	1146
Black	1.3	1213	2.1	1207	4.0	1897
White	1.9	1741	2.3	1742	2.8	3206
Under age 5	1.3	448	1.6	443	3.8	2869
Age 5 and over	1.9	3155	2.3	3154	2.7	3362
Poor	2.4	1142	2.6	1142	4.6	1835
Under age 5	0.0	106	.8	105	6.8	732
Age 5 and over	2.8	1036	2.9	1037	3.1	1103
Not Poor	1.5	1916	2.2	1912	2.7	3444
Under age 5	1.1	264	1.1	262	3.0	1690
Age 5 and over	1.6	1652	2.3	1650	2.4	1754

[1] Limited to children of preschool or regular school attendance age.

Note: N=sample size.

Table source: Mott & Quinlan (1991), Tables 1A and 1B.

Data source: National Longitudinal Survey of Youth

Table 19. Percent of Children with Physical, Emotional, or Mental Condition Requiring Special Assistance, by Ethnicity, Age, and Poverty Status: 1988

HIGHLIGHTS

- The percentage of children requiring attention or treatment of a problem by a doctor or other professional is 5.1% with only limited variability by other characteristics.

- Regular medicine use is required by 3.9% and special equipment is needed by 1.5%.

EXPLANATORY NOTES

These data are from the National Longitudinal Survey of Youth (NLSY). The child health section of the child supplement collects information from the mother every two years on the child's health limitations, accidents and injuries, medical treatment in the last 12 months and health insurance coverage.

The children of the sampled women are representative of American children who have been born to American mothers who were 23 to 31 years of age on January 1, 1988.

Table 19. Percent of Children with Physical, Emotional, or Mental Condition Requiring Special Assistance, by Ethnicity, Age, and Poverty Status: 1988
(Weighted Population Estimates)

Characteristic	Percent Requiring Attention or Treatment from a Doctor or Other Professional		Percent with Problem Requiring Regular use of Any Medicine or Drug		Percent with Problem Requiring Use of Any Special Equipment (e.g., braces, wheelchair).	
	%	N	%	N	%	N
Total	5.1	6226	3.9	6220	1.5	6206
Hispanic	5.1	1148	4.3	1147	1.3	1140
Black	4.1	1876	3.5	1875	0.8	1869
White	5.4	3206	3.9	3198	1.7	3197
Under age 5	4.6	2872	3.1	2870	1.6	2861
Age 5 and over	5.5	3354	4.6	3350	1.4	3345
Poor	6.0	1829	4.0	1831	1.5	1824
Under age 5	7.0	727	3.5	732	2.2	733
Age 5 and over	5.2	1097	4.4	1098	1.0	1097
Not Poor	4.8	3446	3.8	3439	1.3	3436
Under age 5	3.9	1692	3.0	1689	1.4	1688
Age 5 and over	5.7	1754	4.6	1750	1.3	1748

Note: N=sample size.

Table source: Mott & Quinlan (1991), Tables 2A and 2B.

Data source: National Longitudinal Survey of Youth

Table 20. Nature of Health Limitations for Children with a Limitation: Percent Distribution by Ethnicity, Age, and Poverty Status: 1988

HIGHLIGHTS

- The most commonly reported childhood health problems are asthma (27.1%) and allergic conditions (10.4%). There are racial variations in the tendency to report these and other limitations. For example, of the 27.1% of children who have asthma, 46.2% are Hispanic children. This is double the rate reported among white children (23.4%).

EXPLANATORY NOTES

These data are from the National Longitudinal Survey of Youth (NLSY). The child health section of the child supplement collects information from the mother every two years on the child's health limitations, accidents and injuries, medical treatment in the last 12 months and health insurance coverage.

The children of the sampled women are representative of American children who have been born to American mothers who were 23 to 31 years of age on January 1, 1988.

Table 20. Nature of Health Limitations for Children with a Limitation: Percent Distribution by Ethnicity, Age, and Poverty Status: 1988 (Weighted Population Estimates).

Health Limitation	Total	Ethnicity			Age		Poverty Status					
									Not Poor		Poor	
		Hispanic	Black	White	Under Age 5	Age 5 and Over	Not Poor	Poor	Under Age 5	Age 5 and Over	Under Age 5	Age 5 and Over
Learning disability	6.7	6.9	11.9	5.5	2.5	9.5	6.9	7.7	3.4	9.1	0.9	12.5
Minimal brain dysfunction, cerebral dysfunction, attention deficit disorder	3.5	4.0	0.7	4.1	5.9	3.6	4.2	2.9	5.1	3.6	0.0	4.9
Hyperkinesis, hyperactivity	3.8	2.3	4.1	3.9	2.4	4.9	1.8	6.3	0.0	3.0	8.3	4.9
Asthma	27.1	46.2	33.4	23.4	25.2	28.4	22.7	36.1	18.8	25.1	32.8	38.3
Respiratory disorder or sinus infection	5.2	1.1	3.1	6.2	4.4	5.8	7.6	1.4	7.0	8.0	0.0	2.3
Speech impairment	2.9	0.0	3.4	3.2	4.5	1.8	3.2	3.4	3.7	2.9	8.3	0.0
Serious hearing difficulty or deafness	3.6	2.8	3.2	3.8	1.7	5.0	4.5	1.5	1.9	6.0	2.1	1.0
Serious difficulty in seeing or blindness	1.4	0.9	1.5	1.5	0.6	2.0	1.7	1.5	0.6	2.4	0.5	2.2
Serious emotional disturbance	2.6	0.0	0.0	3.5	2.8	2.4	2.5	1.8	2.8	2.3	0.0	3.0
Allergic conditions	10.4	4.2	4.5	12.4	9.8	10.6	13.6	6.7	14.9	12.7	4.1	8.6
Orthopedic handicap	7.9	5.1	3.2	9.3	11.5	5.5	8.5	7.1	12.8	5.7	14.2	2.2
Mental retardation	2.2	2.8	0.9	2.4	4.1	0.9	1.5	2.5	3.1	0.5	4.6	1.1
Heart trouble	4.5	5.4	6.2	4.0	8.2	2.0	2.6	7.5	5.6	0.8	11.4	4.8
Chronic nervous disorder	0.2	0.0	0.8	0.1	0.0	0.3	0.0	0.8	0.0	0.0	0.0	1.3
Chronic ear problems or infections	8.6	7.1	1.6	10.4	15.3	4.1	10.2	5.2	18.1	5.3	12.7	0.0
Blood disorder or immune deficiency	1.0	0.0	3.0	0.6	1.0	1.0	0.3	1.5	0.6	1.5	1.2	1.7
Epilepsy/seizures	6.9	7.1	4.3	7.5	8.3	6.0	6.0	10.6	6.3	5.8	13.5	8.6
Other	25.8	16.7	30.9	25.7	26.3	25.4	27.9	24.5	31.1	25.9	18.6	28.6
Sample size	(448)	(80)	(110)	(258)	(158)	(290)	(230)	(150)	(83)	(147)	(47)	(103)
Percent with Limitation for Whole Life	50.0	37.6	54.2	50.6	61.9	42.0	49.7	56.7	63.2	41.3	70.9	47.1
Sample size	(444)	(80)	(109)	(255)	(156)	(288)	(227)	(149)	(82)	(145)	(46)	(103)

Note: Percents add to more than 100 because some respondents had multiple limitations. Sample size in parentheses.

Table source: Mott & Quinlan (1991), Tables 3A and 3B.
Data source: National Longitudinal Survey of Youth

DISABILITY, HEALTH STATUS, AND HEALTH CARE UTILIZATION

Table 21. Conditions with Highest Risk of Disability for Children Under Age 18, by Type of Disability: 1983-1986

HIGHLIGHTS

- Almost 90% of children with mental retardation are limited in activity as a result of that condition, which ranks first, followed by cerebral palsy. Epilepsy and diabetes are two diseases which rank next highest in risk of causing activity limitation, although the level of risk is roughly half that of mental retardation and cerebral palsy. Other selected impairments, which consist mainly of cleft palate and spina bifida (64% and 24% of total, respectively) rank next in risk.

- Among children, conditions with the highest risks of causing major activity limitation are generally the same as those with the highest risks of causing any activity limitation, but their relative risks change. Diabetes and orthopedic impairment in an upper extremity drop in relative risk. Diabetes and orthopedic impairment in an upper extremity limit extracurricular activities more than they limit school activity. Speech impairments rank more highly in risk of causing limitation in school-related activities than in risk of causing limitation in extracurricular activities. More than other conditions, mental retardation and speech impairments limit school-related activities more than they limit extracurricular activities.

- Risks of conditions causing need for help in activities of daily living (ADL) are generally low among children. Cerebral palsy ranks first in risk, and 13.2% of cases cause need for help in ADL. Mental retardation ranks next highest, followed by osteoarthritis/other arthropathies, epilepsy, and other visual impairments. These estimates of risk have low statistical reliability, however, and merely suggest these conditions have high risks of causing need for help in ADL among children.

EXPLANATORY NOTES

This table presents estimates based on analysis of data from the National Health Interview Survey. The analysis is based on four years (1983-1986) of NHIS chronic condition data. Data are estimates (annual averages) based on household interviews of the civilian noninstitutionalized population. The types of disability included are activity limitation, major activity limitation, and need for assistance from another person in basic life activities. Limitation includes inability to perform an activity or restrictions in the kind or amount of activity. Major activity refers to the principal roles associated with a person's age group. For children, the major activity is usual play for children under age 5, and going to school for children aged 5-17. Activities of daily living (ADL) include personal care needs, such as eating, bathing, dressing, or getting around the home. Need for assistance with ADL is asked of persons beginning at age 5 if they report having any activity limitation.

Condition categories used in the NHIS include many conditions that have very low prevalence among children. Therefore, estimates of disability risks for all specific conditions among children are not presented. However, disability risks were estimated for specific conditions and ranked in terms of highest risk.

Table 21. Conditions with Highest Risk of Disability for Children Under Age 18, by Type of Disability: 1983-1986

Chronic Condition	Number of Conditions (1000s)	Percent Causing Activity Limitation	Rank	Percent Causing Major Activity Limitation	Rank	Percent Causing Need for Help in Activities of Daily Living	Rank§
Mental Retardation	661	89.7	1	87.1	1	5.9*	2
Cerebral palsy	108	73.8	2	59.8	2	13.2*	1
Epilepsy	332	38.2	3	23.9	4	1.6*	4
Diabetes	119	35.3	4	11.9*	9	0.0	--
Other selected impairments	115	30.8*	5	23.4*	5	0.0	--
Deaf in both ears	102	30.6*	6	22.5*	6	0.0	--
Orthopedic impairment in upper extremity	132	27.0*	7	9.4*	13	0.0	--
Speech impairments	1,094	26.2	8	25.8*	3	0.0	--
Other heart disease/disorders†	287	21.3	9	11.9*	10	0.0	--
Asthma	2,926	19.7	10	12.9	7	0.1*	--
Osteomyelitis/bone disorders	132	18.2*	11	9.6*	12	0.0	--
Orthopedic impairment in lower extremity	1,258	16.8	12	4.1*	--	0.5*	--
Absence of fingers, toes, feet	70	16.1*	13	10.3*	11	0.0	--
Hypertension	138	14.6*	14	12.0*	8	0.0	--
Kidney disorders	262	12.3*	15	8.2*	15	0.0	--
Osteoarthritis/other arthropathies	113	11.2*	--	8.5*	14	3.3*	3
Other visual impairment/eye disorders	656	10.3	--	5.8*	--	1.4*	5

*Figure has low statistical reliability or precision (relative standard error exceeds 30 percent).

† Valve disorders (6%), congenital disorders (70%), all other and ill-defined heart conditions (24%).

§ Ranking includes only the five conditions with the highest risk due to low statistical reliability of estimates.

Table source: LaPlante (1991b), Table C.

Data source: National Health Interview Survey, 1983-1986

Table 22. Average Annual Percent Distribution and Number of Persons by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

HIGHLIGHTS

- About 7% of persons under 18 years of age were limited in activity, in fair or poor health, or both. For youth ages 18-24, the proportion is slightly higher at 8.6%.

- Of those 7% of children under 18 years who were limited in activity, in fair or poor health, or both, 12.9% (.9% divided by 7%) were both limited and in fair or poor health. For youth ages 18-24, 13.9% were both limited and in fair or poor health.

- Relative differences according to sex within each age group are minor. In children under 5 years of age, 2.5% of boys and 2.1% of girls are limited in activity. For boys 5-17 year of age, 7.3% are limited while 5.1% of girls are limited. Among youth ages 18-24, limitations are found in 6.1% of men and 5.4% of women.

- Differences between white and black children are also small. Among white children under 5 years, 2.2% are limited in activity, and 3.2% of black children are limited. For the ages 5-17 years, 6.3% of white children and 6.5% of black children have limitations. For white and black youth ages 18-24, the percentages having limitations are 5.8% and 5.5%, respectively.

EXPLANATORY NOTES

The data in this table come from combining all of the individuals included in the National Health Interview Survey sample from 1984 to 1988, amounting to an overall sample of about 504,000 persons. Combining five years of sample respondents produces estimates cross-classified by health status and limitation in activity while avoiding high sampling errors associated with producing estimates on subgroups who comprise a small proportion of the total population.

Persons are classified as limited or not limited in activity (their degree of limitation being disregarded) and as in fair or poor health (combined) or in good, very good, or excellent health (combined).

Estimates were produced by summing the frequencies for the five year period and dividing by five. Thus, the frequencies, percents, and rates in the table represent average annual estimates for the five year period and not estimates for the whole period. Estimates restricted to age, sex, or race categories are adjusted to U.S. Bureau of the Census estimates and therefore have no sampling variation.

Health status is ascertained by asking the question: "Would you say ________'s health in general is excellent, very good, good, fair, or poor?"

Limitation of activity is defined in terms of level of ability to perform major activities associated with specific age ranges. For children under age 5, the usual activity is play; for children aged 5-17 it is going to school, for persons 18 years and older it is working and keeping house.

Table 22. Average Annual Percent Distribution and Number of Persons by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

Characteristic	Total[1]	Limited in activity		Not limited in activity		Total[2]	Limited in activity		Not limited in activity	
		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health
	Percent distribution					Number in thousands				
Age										
Under 18 years	100.0	0.9	4.2	1.9	93.0	63,035	568	2,632	1,160	58,170
Under 5 years	100.0	0.7	1.6	2.3	95.5	18,154	118	295	406	17,181
5 - 17 years	100.0	1.0	5.3	1.7	92.0	44,882	450	2,338	754	10,989
18 - 24 years	100.0	1.2	4.5	2.9	91.4	26,790	323	1,206	779	24,383
Sex and age										
Male, under 5 years	100.0	0.7	1.8	2.5	95.0	9,290	65	166	226	8,755
Male, 5 - 17 years	100.0	1.1	6.2	1.5	91.2	22,936	244	1,422	340	20,750
Male, 18 - 24 years	100.0	1.1	5.0	2.2	91.7	13,082	147	647	289	11,943
Female, under 5 years	100.0	0.6	1.5	2.0	95.9	8,864	53	129	180	8,426
Female, 5 - 17 years	100.0	0.9	4.2	1.9	92.9	21,946	206	916	414	20,240
Female, 18 - 24 years	100.0	1.3	4.1	3.6	91.0	13,708	175	559	490	12,439
Race and age										
White, under 5 years	100.0	0.6	1.6	2.0	95.9	14,742	84	229	286	14,027
White, 5 - 17 years	100.0	0.9	5.4	1.4	92.3	36,562	324	1,960	493	33,512
White, 18 - 24 years	100.0	1.1	4.7	2.5	91.7	22,155	246	1,033	548	20,247
Black, under 5 years	100.0	1.1	2.1	3.8	93.0	2,771	31	58	103	2,548
Black, 5 - 17 years	100.0	1.6	4.9	3.4	90.0	6,874	112	335	231	6,131
Black, 18 - 24 years	100.0	1.9	3.6	5.1	89.4	3,688	69	133	189	3,282

[1] Excludes persons whose health status was not assessed.
[2] Includes persons whose health status was not assessed.

Table source: Ries & Brown (1991), Table 2.
Data source: National Health Interview Survey, 1984-88

Table 23. Average Annual Number Per Person Per Year and Number of Restricted Activity Days, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

HIGHLIGHTS

- Estimates for average number of restricted activity days per person per year differ widely based on health status and whether or not the person is limited in activity. For example, among children of all ages and races, the highest number of restricted activity days are for children who are both limited in activity and in fair or poor health. For these children, the average number per person per year of restricted days ranges from 41.1 for black children ages 5-17 years and 89.9 days for white children under age 5. The least number of restricted activity days are among children who are not limited in activity and are in good to excellent health. Among these children, restricted activity days ranged from 5.6 to 9.2 days per year.

EXPLANATORY NOTES

The data in this table come from combining all of the individuals included in the National Health Interview Survey sample from 1984 to 1988, amounting to an overall sample of about 504,000 persons. Combining five years of sample respondents produces estimates cross-classified by health status and limitation in activity while avoiding high sampling errors associated with producing estimates on subgroups who comprise a small proportion of the total population.

Persons are classified as limited or not limited in activity (their degree of limitation being disregarded) and as in fair or poor health (combined) or in good, very good, or excellent health (combined).

Estimates were produced by summing the frequencies for the five year period and dividing by five. Thus, the frequencies, percents, and rates in the table represent average annual estimates for the five year period and not estimates for the whole period. Estimates restricted to age, sex, or race categories are adjusted to U.S. Bureau of the Census estimates and therefore have no sampling variation.

Health status is ascertained by asking the question: "Would you say ________'s health in general is excellent, very good, good, fair, or poor?"

Limitation of activity is defined in terms of level of ability to perform major activities associated with specific age ranges. For children under age 5, the usual activity is play; for children aged 5-17 it is going to school, for persons 18 years and older it is working and keeping house.

A restricted-activity day is a day on which a person stays in bed, misses work or school, or cuts down on his or her usual activity because of illness, impairment, or injury.

Table 23. Average Annual Number Per Person Per Year and Number of Restricted Activity Days, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

Characteristic	Total[1]	Limited in activity		Not limited in activity		Total[1]	Limited in activity		Not limited in activity	
		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health
	Number per person per year					Number in thousands				
Age										
Under 5 years	10.2	84.4	24.9	34.6	8.8	184,942	9,955	7,360	14,035	151,905
5 - 17 years	8.8	56.9	18.0	22.2	7.5	395,341	25,618	42,137	16,723	307,667
18 - 24 years	9.6	71.4	25.0	26.9	7.5	258,194	23,047	30,142	20,934	183,369
Sex and age										
Male, under 5 years	10.3	81.4	25.9	33.8	8.8	95,678	5,294	4,303	7,644	77,410
Male, 5 - 17 years	8.2	52.3	16.4	21.0	6.9	186,981	12,754	23,291	7,148	142,390
Male, 18 - 24 years	7.7	67.1	22.4	21.2	5.8	100,399	9,868	14,484	6,124	69,666
Female, under 5 years	10.1	87.9	23.7	35.5	8.8	89,263	4,661	3,056	6,391	74,495
Female, 5 - 17 years	9.5	62.4	20.6	23.1	8.2	208,360	12,863	18,846	9,575	165,277
Female, 18 - 24 years	11.5	75.3	28.0	30.2	9.1	157,795	13,179	15,658	14,810	113,703
Race and age										
White, under 5 years	10.6	89.9	26.9	38.9	9.2	155,838	7,555	6,167	11,138	129,631
White, 5 - 17 years	9.2	60.9	18.6	26.0	7.9	338,095	19,721	36,437	12,804	266,231
White, 18 - 24 years	9.9	73.5	25.4	28.8	7.8	218,374	18,084	26,215	15,790	157,849
Black, under 5 years	8.8	67.0	17.9	25.8	7.3	24,468	2,078	1,039	2,655	18,491
Black, 5 - 17 years	7.0	41.1	15.9	15.0	5.6	48,246	4,602	5,326	3,473	34,635
Black, 18 - 24 years	8.8	64.4	26.0	24.1	6.0	32,454	4,454	3,452	4,557	19,726

[1] Includes persons whose health status was not assessed.

Table source: Ries & Brown (1991), Table 3.

Data source: National Health Interview Survey, 1984-88

Table 24. Average Annual Number Per Person Per Year and Number of Physician Contacts, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

HIGHLIGHTS

- The estimates for physician contacts ranged from 2.8 per child per year for children 5-17 years of age not limited in activity and in good to excellent health, to 28.2 per child per year for children under 5 years who were limited and in fair or poor health.

- White children under age 18 who were limited and in fair or poor health had twice as many physician contacts than black children (22.3 contacts per child per year versus 10 contacts).

EXPLANATORY NOTES

The data in this table come from combining all of the individuals included in the National Health Interview Survey sample from 1984 to 1988, amounting to an overall sample of about 504,000 persons. Combining five years of sample respondents produces estimates cross-classified by health status and limitation in activity while avoiding high sampling errors associated with producing estimates on subgroups who comprise a small proportion of the total population.

Persons are classified as limited or not limited in activity (their degree of limitation being disregarded) and as in fair or poor health (combined) or in good, very good, or excellent health (combined).

Estimates were produced by summing the frequencies for the five year period and dividing by five. Thus, the frequencies, percents, and rates in the table represent average annual estimates for the five year period and not estimates for the whole period. Estimates restricted to age, sex, or race categories are adjusted to U.S. Bureau of the Census estimates and therefore have no sampling variation.

Health status is ascertained by asking the question: "Would you say ________'s health in general is excellent, very good, good, fair, or poor?"

Limitation of activity is defined in terms of level of ability to perform major activities associated with specific age ranges. For children under age 5, the usual activity is play; for children aged 5-17 it is going to school, for persons 18 years and older it is working and keeping house.

A physician contact is defined as a contact with a physician or a medical assistant working under the supervision of a physician for purposes of treatment, diagnosis, or consultation. Contacts of this nature over the telephone are included, but contacts with medical personnel while an overnight patient in a hospital are not. Visits to a hospital clinic or emergency room are included.

Table 24. Average Annual Number Per Person Per Year and Number of Physician Contacts, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984 - 1988.

		Limited in activity		Not limited in activity			Limited in activity		Not limited in activity	
Characteristic	Total[1]	Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health	Total[1]	Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health
	Number per person per year					Number in thousands				
Age										
Under 5 years	6.6	28.2	14.3	14.8	6.1	119,676	3,328	4,220	5,998	105,327
5 - 17 years	3.3	16.4	7.7	6.6	2.8	146,154	7,363	17,975	4,989	114,940
18 - 24 years	4.2	17.2	8.5	9.2	3.6	111,521	5,551	10,213	7,186	88,265
Sex and age										
Male, under 18 years	4.2	19.4	8.1	9.5	3.8	136,841	5,964	12,862	5,391	111,630
Female, under 18 years	4.2	18.3	8.9	9.4	3.8	128,989	4,727	9,334	5,597	108,637
Race and age										
White, under 18 years	4.5	22.3	8.9	11.7	4.1	232,040	9,105	19,428	9,077	192,928
Black, under 18 years	2.9	10.0	6.1	4.7	2.5	27,696	1,426	2,413	1,569	22,122

[1] Includes persons whose health status was not assessed.

Table source: Ries & Brown (1991), Table 4.

Data source: National Health Interview Survey, 1984-88

Table 25. Average Annual Number Per 100 Persons Per Year and Number of Short-stay Hospital Days, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988

HIGHLIGHTS

- Children ages 5-17 who were not limited in activity and who were in good to excellent health had 11.8 hospital days per 100 children per year, but children under age 5 who were limited and in fair to poor health had a corresponding rate of 1,582.3 days.

EXPLANATORY NOTES

The data in this table come from combining all of the individuals included in the National Health Interview Survey sample from 1984 to 1988, amounting to an overall sample of about 504,000 persons. Combining five years of sample respondents produces estimates cross-classified by health status and limitation in activity while avoiding high sampling errors associated with producing estimates on subgroups who comprise a small proportion of the total population.

Persons are classified as limited or not limited in activity (their degree of limitation being disregarded) and as in fair or poor health (combined) or in good, very good, or excellent health (combined).

Estimates were produced by summing the frequencies for the five year period and dividing by five. Thus, the frequencies, percents, and rates in the table represent average annual estimates for the five year period and not estimates for the whole period. Estimates restricted to age, sex, or race categories are adjusted to U.S. Bureau of the Census estimates and therefore have no sampling variation.

Health status is ascertained by asking the question: "Would you say ________'s health in general is excellent, very good, good, fair, or poor?"

Limitation of activity is defined in terms of level of ability to perform major activities associated with specific age ranges. For children under age 5, the usual activity is play; for children aged 5-17 it is going to school, for persons 18 years and older it is working and keeping house.

A hospital day is a measure of the number of nights a person spent as an admitted patient in a short-stay hospital.

Table 25. Average Annual Number Per 100 Persons Per Year and Number of Short-stay Hospital Days, by Limitation of Activity Due to Chronic Conditions, Respondent-assessed Health Status, and Selected Characteristics: 1984-1988.

Characteristic	Total[1]	Limited in activity		Not limited in activity		Total[1]	Limited in activity		Not limited in activity	
		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health		Fair or poor health	Good to excellent health	Fair or poor health	Good to excellent health
	Number per 100 persons per year					Number in thousands				
Age										
Under 5 years	51.7	1,582.2	220.0	321.7	31.9	9,387	1,867	649	1,306	5,481
5 - 17 years	20.2	345.6	88.5	65.3	11.8	9,045	1,555	2,069	492	4,826
18 - 24 years	47.2	476.8	146.8	134.3	33.9	12,648	1,540	1,771	1,046	8,262
Sex and age										
Male, under 18 years	28.0	378.2	96.5	137.3	18.4	9,038	1,165	1,533	77	5,422
Female, under 18 years	30.5	871.4	113.4	171.9	17.0	9,394	2,257	1,185	1,021	4,886
Race and age										
White, under 18 years	27.8	596.1	103.4	160.2	17.3	14,279	2,432	2,264	1,248	8,215
Black, under 18 years	39.5	655.9	111.7	147.6	21.7	3,812	938	439	493	1,884

[1] Includes persons whose health status was not assessed.

Table source: Ries & Brown (1991), Table 5.

Data source: National Health Interview Survey, 1984-88

Table 26. Percent Distribution of Type of Insurance Coverage for Chronically Ill Children with Special Needs by Selected Characteristics: 1988

HIGHLIGHTS

- About three-fourths (76.2%) of the children had private insurance coverage, 11% had Medicaid coverage, and 12.8% had neither private insurance nor Medicaid coverage.

- Black and Hispanic chronically ill children with special needs were much less likely to have private insurance and more likely to have Medicaid coverage than were white chronically ill children. Hispanic children (23.4%) were almost twice as likely as non-Hispanic children (12%) to have neither private nor public insurance coverage.

- Children in families with incomes of less than $25,000 were much less likely to have private insurance coverage and substantially more likely to be uninsured (22.6%) compared with children from families with annual family incomes of $25,000 or more (5.5%).

- Children who lived in central cities were also less likely to have private insurance (67.5%) and more likely to be uninsured (15.8%) than were children who lived in more suburban areas, 84.1% and 10.1%, respectively. Those who lived outside of metropolitan areas were also less likely to have private insurance coverage (71.1%) and more likely to be uninsured (14.6%).

EXPLANATORY NOTES

The children represented in this table were identified to have had one or more of a number of childhood conditions in the NHIS-CH condition record. Respondents were asked whether the child had ever had the condition; if so, whether they had it in the last 12 months. For selected conditions, those who had experienced it in the last year were asked whether it had lasted at least 3 months.

For conditions that met these criteria, the respondent was asked whether the child missed any school, stayed in bed, or otherwise limited usual activities. Also asked was how much pain, discomfort, or bother the child has experienced during the past 12 months due to the condition. The respondent was also asked the number of nights, if any, the child has been hospitalized, the number of times a medical professional was consulted about the child's condition, and if the child has used prescribed medicine for the condition during the past 12 months.

Chronically ill children with special needs were defined as having one or more of the designated conditions, who were unable to engage in usual childhood activities, or experienced pain or discomfort often or all of the time. In addition, based on questions in the main questionnaire, children with one or more of the chronic conditions were considered to have special needs, including those who reported that due to illness they were unable to perform or were limited in the kind or amount of their major activities (defined as play for children under 5 years of age and going to school for those aged 5 to 17).

Table 26. Percent Distribution of Type of Insurance Coverage for Chronically Ill Children with Special Needs by Selected Characteristics: 1988

Characteristic	Number of children in thousands	Total %	Percent Distribution of Insurance Coverage: Private Insurance	Medicaid	Neither
All children[1]	9,150	100	76.2	11.0	12.8
Age					
Under 5 years	2,713	100	75.3	11.9	12.8
5 - 17 years	6,437	100	76.5	10.6	12.9
Sex					
Male	4,895	100	75.2	11.3	13.5
Female	4,254	100	77.3	10.7	12.1
Race					
White	7,818	100	80.2	7.8	12.1
Black	1,114	100	51.5	34.1	14.2
Hispanic origin					
Hispanic	784	100	53.5	23.2	23.4
Non-Hispanic	8,198	100	78.2	9.8	12.0
Family structure					
Biological mother and father	5,677	100	86.1	3.2	10.6
Biological mother only	2,834	100	58.9	24.9	16.2
All other	638	100	64.6	18.2	17.4
Family income					
Less than $25,000	3,414	100	52.7	24.7	22.6
$25,000 or more	5,003	100	93.2	1.4	5.5
Place of residence					
MSA, central city	2,557	100	67.5	16.7	15.8
MSA, not central city	4,287	100	84.1	5.8	10.1
Not MSA	2,306	100	71.1	14.3	14.6

[1] Numbers for respective groups may not sum to total due to missing values.

Note: The total number of cases in this table is less than the total number of children with special needs due to missing values on insurance coverage.

Table source: Aday (1992), Table 3.

Data source: National Health Interview Survey of Child Health

Table 27. Physician Utilization, Hospital Utilization, and Use of Medicine of Chronically Ill Children with Special Needs by Selected Characteristics: 1988

HIGHLIGHTS

- More than 8 of every 10 (83.8%) chronically ill children with special needs had contact with a physician during the year. Those who did averaged 7.9 visits. Children under 5 years of age (93.7%) were more likely to have seen a physician than were children 5 to 17 years of age (80%). Among children who saw a physician, the mean number of visits was lower for: (a) children 5-17 years of age (7.3) compared with children under 5 years (9.1); (b) for black children (4.9) compared with white children (8.4); and (c) for children who lived with their biological mother only (6.2) compared with children who lived with both parents (8.7). Mean visits were also lower for children in families earning less than $25,000 (6.9) compared with families earning $25,000 or more (8.9), as well as for children living in central cities of metropolitan areas (7.0) compared with children living in more suburban areas (8.3).

- About 9% of the children had been hospitalized at least once during the year. Children under 5 years of age (12.3%) were more likely to have been hospitalized than were children aged 5-17 years (7.3%). Though the differences were not statistically significant, there was a tendency for minority and low-income children, who averaged fewer visits to a physician in the past year, to be more likely to be hospitalized.

- Nearly 80% of the children had taken prescribed medicine during the past year. The percentages taking medication were higher for younger children (89.5%) compared with older children (74.6%), for white children (80.1%) compared with black children (73.7%), and for children who lived with a biological mother and father (81.7%) or a biological mother (75.8%) compared with children who lived with neither biological parent (70.9%).

EXPLANATORY NOTES

The children represented in this table were identified to have had one or more of a number of childhood conditions in the NHIS-CH condition record. Respondents were asked whether the child had ever had the condition; if so, whether they had it in the last 12 months. For selected conditions, those who had experienced it in the last year were asked whether it had lasted at least 3 months.

For conditions that met these criteria, the respondent was asked whether the child missed any school, stayed in bed, or otherwise limited usual activities. Also asked was how much pain, discomfort, or bother the child has experienced during the past 12 months due to the condition. The respondent was also asked the number of nights, if any, the child has been hospitalized, the number of times a medical professional was consulted about the child's condition, and if the child has used prescribed medicine for the condition during the past 12 months.

Chronically ill children with special needs were defined as having one or more of the designated conditions, who were unable to engage in usual childhood activities, or experienced pain for discomfort often or all of the time. In addition, based on questions in the main questionnaire, children with one or more of the chronic conditions were considered to have special needs, including those who reported that due to illness they were unable to perform or were limited in the kind or amount of their major activities (defined as play for children under 5 years of age and going to school for those aged 5 to 17).

Table 27. Physician Utilization, Hospital Utilization, and Use of Medicine of Chronically Ill Children with Special Needs by Selected Characteristics: 1988

	Physician utilization		Hospital utilization	Use of medicine
Characteristic	Children with 1 contact or more for condition in past year (percent)	Contacts per child per year for those with 1 contact or more (mean number)	Children with 1 night or more for condition in past year (percent)	Children using medicine for condition in past year (percent)
All children	83.8	7.9	8.8	79.0
Age				
Under 5 years	93.7	9.1	12.3	89.5
5 - 17 years	80.0	7.3	7.3	74.6
Sex				
Male	83.1	8.3	9.6	79.3
Female	84.5	7.3	7.9	78.7
Race				
White	84.1	8.4	8.5	80.1
Black	84.5	4.9	11.1	73.7
Hispanic origin				
Hispanic	81.2	6.5	11.5	75.6
Non-Hispanic	84.0	8.0	8.5	79.3
Family structure				
Biological mother and father	86.3	8.7	8.2	81.7
Biological mother only	81.1	6.2	9.8	75.8
All other	75.0	7.6	9.0	70.9
Family income				
Less than $25,000	83.3	6.9	10.6	78.3
$25,000 or more	84.7	8.9	7.4	79.5
Place of residence				
MSA, central city	85.1	7.0	8.7	77.6
MSA, not central city	84.6	8.3	8.3	80.6
Not MSA	80.8	8.0	9.8	77.7
Insurance coverage				
Private insurance	84.3	8.0	8.0	79.6
Medicaid	85.5	6.9	13.5	75.7
Neither	76.8	8.2	5.4	77.6

Table source: Aday (1992), Tables 4 and 5.

Data source: National Health Interview Survey of Child Health

Table 28. Assistive Devices Used by Youth With Disabilities by Disability Category: 1985-86

HIGHLIGHTS

- Among hard of hearing and deaf special education students ages 13 to 21 in the 1985-86 school year, hearing aids were the most commonly used assistive device with 72.1% of hard of hearing and 76.5% of deaf students using them.

- Wheelchairs were used by only 2.2% of all disabled students, but were used by 45.3% of orthopedically impaired students. Another 25% of orthopedically impaired used crutches, canes or walkers, and 20.4% used prosthetics or orthotics.

- Among students with visual impairments, 62.7% used Braille or large print readers, 22.9% used opticon or optical scanner, and 20.4% used computers to aid vision.

EXPLANATORY NOTES

These data were collected in 1987 by the National Longitudinal Transition Study of Special Education Students (NLTS) from a sample of more than 8,000 youth who represent the national population of secondary special education students who were ages 13 to 21 in the 1985-86 school year.

Percentages and means are weighted to represent the national population of youth with disabilities and youth in each disability category. Reported percentages are based on those for whom the question was appropriate and who answered the question. Some items permitted more than one response so that percentages often will not add to 100%. The approximate standard errors increase as the sample size decreases, so percentages based on small samples should be interpreted with caution.

Items related to assistive devices were not asked of parents of youth in all disability categories in an effort to reduce the burden of the interview and because some devices were assumed to be inappropriate to some kinds of disabilities.

Items related to assistive devices for the hearing impaired (telecommunications devices, telephone amplifier, hearing aid, closed captioned TV, other hearing assistance) were asked only of parents of youth who were reported as deaf, hard of hearing, deaf/blind, or multiply disabled as a primary or additional disability by the school or parent.

Assistive devices related to mobility (wheelchair, crutches, cane, walker, changes to the car, prosthetics, orthotics, computer designed to aid mobility, other devices to aid mobility) were asked only of parents of youth who were reported as orthopedically impaired, other health impaired, or multiply disabled as a primary or additional disability by the school or parent.

Assistive devices related to vision (seeing eye dog, Braille or large print readers, opticon/optical scanner, computers to aid vision, other vision assistance) were asked of parents of youth reported as visually impaired, deaf/blind, or multiply disabled as a primary or additional disability.

Youth whose parents were not asked directly about assistive devices were coded as not using the devices, assuming they were inappropriate to the disabilities of the youth. If some youth actually used the devices, but parents were not asked the items, the reported data would underestimate use of assistive devices.

Table 28. Assistive Devices Used by Youth With Disabilities by Disability Category: 1985-86

Percent Reporting Using Assistive Devices	Total	Primary Disability Category										
		Learning Disabled	Emotionally Disturbed	Speech Impaired	Mentally Retarded	Visually Impaired	Hard of Hearing	Deaf	Orthoped-ically Impaired	Other Health Impaired	Multiply Disabled	Deaf/ Blind
Telecommunications device	0.7	0.0	0.0	0.2	0.0	0.1	16.8	57.4	0.0	0.1	0.6	12.6
Telephone amplifier	0.6	0.4	0.1	0.2	0.1	0.2	22.3	15.3	0.0	0.4	0.3	0.5
Hearing aid	2.1	0.3	0.6	2.4	1.2	2.7	72.1	76.5	1.2	1.9	3.0	46.9
Closed captioned TV	0.7	0.0	0.1	0.3	0.0	0.4	21.0	54.0	0.0	0.1	0.3	9.1
Other hearing assistance	0.2	0.1	0.0	0.3	0.2	0.0	3.0	5.7	0.0	0.3	0.1	1.7
Number of respondents	6681	958	622	478	839	714	665	739	605	395	585	76
A wheelchair	2.2	0.2	0.2	0.4	4.0	5.7	0.5	1.6	45.3	10.8	28.4	3.0
Crutches, cane, walker	1.3	0.3	0.4	0.4	2.1	4.3	0.1	1.9	25.0	7.0	10.9	0.0
Modifications to a car	0.3	0.0	0.0	0.0	0.3	1.5	0.1	0.3	10.5	1.9	2.5	0.0
Prosthetics/orthotics	1.4	0.5	0.7	1.0	1.9	2.4	0.8	0.9	20.4	8.8	14.3	3.3
Computers to aid mobility	1.0	0.6	0.1	0.2	1.0	1.8	0.8	0.3	13.8	5.2	6.5	0.0
Other mobility assistance	0.3	0.3	0.0	0.0	0.4	0.2	0.0	0.1	2.6	1.4	2.1	0.0
Number of respondents	6576	947	611	473	815	701	624	757	616	394	558	79
Seeing eye dog	0.0	0.0	0.0	0.0	0.0	0.6	0.0	0.0	0.0	0.0	0.0	0.0
Braille or large print readers	0.9	0.2	0.2	0.4	0.9	62.7	0.1	0.2	1.7	0.1	2.4	18.0
Opticon/optical scanner	0.2	0.1	0.0	0.0	0.0	22.9	0.0	0.1	1.3	0.0	0.5	2.8
Computers to aid vision	0.2	0.0	0.0	0.0	0.2	20.4	0.2	0.2	1.6	0.5	0.8	1.5
Other vision assistance	0.3	0.1	0.0	0.0	0.4	11.3	0.0	0.1	1.9	0.3	1.2	10.3
Number of respondents	6600	958	619	477	838	661	634	763	602	393	584	69

Note: Percentages do not add to 100% because items permitted more than one response.
Table source: Valdes, Williamson, & Wagner (1990), Table 7A.
Data source: National Longitudinal Transition Study of Special Education Students

CHILDREN IN RESIDENTIAL PLACEMENTS

Table 29. Number and Percent of Children Receiving Partial Care Services at Year End, by Type of Organization: 1988

HIGHLIGHTS

- At the end of 1988, of the nearly 224,000 persons receiving partial care services, 38,979, or 17.4% were children under the age of 18. In terms of age, 67.7% of the partial care patients in Residential Treatment Centers (RTCs) were children.

EXPLANATORY NOTES

Data for this table were obtained from the 1988 Inventory of Mental Health Organizations and the 1988 Inventory of General Hospital Mental Health Services.

Partial care is a relatively new and rapidly growing form of mental health care. It is intermediate between inpatient or residential care and outpatient care and consists of a planned program of mental health treatment services generally provided in visits of three or more hours to groups of clients.

Table 29. Number and Percent of Children Receiving Partial Care Services at Year End, by Type of Organization: 1988

Type of Organization	Age				Total	Children as a percentage of all clients
	Less than 13 Years		13 - 17 Years			
All organizations	22148	100%	16831	100%	38979	17.4
State and county mental hospitals	978	4%	662	4%	1640	9.4
Private psychiatric hospitals	934	4%	1266	8%	2200	27.6
Non-federal general hospital psychiatric services	1336	6%	1055	6%	2391	15.2
VA mental health services	6	0.03%	0	0%	6	.1
Residential Treatment Centers for Emotionally Disturbed Children	3142	14%	2146	13%	5288	67.7
Freestanding psychiatric partial care organizations	1397	6%	1226	7%	2623	24.2
Multiservice mental health organizations	14355	65%	10476	62%	24831	16.1

Table source: Sunshine, Witkin, Atay, & Manderscheid (1992), Tables 8 and 9.

Data source: Inventory of Mental Health Organizations/Inventory of General Hospital Mental Health Services, 1988

Table 30. Distribution of Children in State Institutions by Level of Mental Retardation and Age on June 30, 1991

HIGHLIGHTS

- This table shows the distribution of state institution residents by age and level of mental retardation groups. Within state institutions, children who are older have more severe cognitive limitations than children who are younger. For example, 70.3% of residents who had profound mental retardation were between the ages of 15 and 21. This same age group represents 73.9% of all children in state institutions.

- The majority of children in state institutions have profound mental retardation. This is true across all age groups.

EXPLANATORY NOTES

The information about characteristics of state institution residents in fiscal year 1991 is based on a mail survey of 288 individual state institutions for persons with mental retardation and related conditions with 16 or more residents operating in the United States on June 30, 1991. These facilities included traditional state mental retardation/developmental disabilities (MR/DD) institutions and MR/DD units contained within other state-operated institutions. The survey was conducted by the University of Minnesota, Center on Residential Services and Community Living and the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (NASPRFMR) as part of the National Recurring Data Set Project on Residential Services.

Table 30. Distribution of Children in State Institutions by Level of Mental Retardation and Age on June 30, 1991

Level of Mental Retardation	Chronological Age			Total
	0 - 9	10 - 14	15 - 21	
Mild +	12 (2.6%) [2.3%]	39 (8.7%) [3.9%]	397 (88.6%) [9.2%]	448 (100.0%) [7.7%]
Moderate	12 (2.5%) [2.3%]	64 (13.5%) [6.3%]	398 (83.9%) [9.2%]	474 (100.0%) [8.1%]
Severe	43 (4.9%) [8.3%]	151 (17.4%) [15.0%]	670 (77.5%) [15.5%]	864 (100.0%) [14.8%]
Profound	452 (11.1%) [87.1%]	754 (18.6%) [74.8%]	2848 (70.3%) [66.0%]	4054 (100.0%) [69.4]
Total	519 (8.9%) [100.0%]	1008 (17.3%) [100.0%]	4313 (73.9%) [100.0%]	5840 (100.0%) [100.0%]

Note: The percentage in parentheses indicates the distribution of children with different levels of mental retardation. The percentage in brackets indicates the distribution of children by level of mental retardation within the different age categories. Statistics are based on the reports of state institutions housing 66,783 (84.1%) of the 79,407 residents of state institutions on June 30, 1991.

Table source: Lakin, Blake, Prouty, Mangan, & Bruininks (1993), Table 1.8.

Table 31. New Admissions, Readmissions to, and Discharges from State Institutions by Age and Level of Mental Retardation in the Year Ending June 30, 1991

HIGHLIGHTS

- Children and youth up to age 21 made up 29.8% of all new admissions to state institutions in fiscal year 1991. Youth in the age group of 15-21 comprised the greatest proportion of children (18.4%) and were equally likely to be admitted for mild or profound mental retardation. Profound mental retardation was more common among younger children admitted to state institutions.

- The proportion of children and youth among all readmissions was 19%. As with new admissions, the largest proportion of readmissions was among youth ages 15-21 (13.6%), but within this age group more youth had mild mental retardation than any other form of mental retardation.

- Children and youth comprised 11.8% of all discharges from state institutions in fiscal year 1991.

EXPLANATORY NOTES

The information about characteristics of state institution residents in fiscal year 1991 is based on a mail survey of 288 individual state institutions for persons with mental retardation and related conditions with 16 or more residents operating in the United States on June 30, 1991. These facilities included traditional state mental retardation/developmental disabilities (MR/DD) institutions and MR/DD units contained within other state-operated institutions. The survey was conducted by the University of Minnesota, Center on Residential Services and Community Living and the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (NASPRFMR) as part of the National Recurring Data Set Project on Residential Services (Lakin, Blake, Prouty, Mangan, & Bruininks, 1993).

Table 31. New Admissions to State Institutions by Age and Level of Mental Retardation in the Year Ending June 30, 1991

Level of Mental Retardation	Chronological Age				Total
	0 - 4	5 - 9	10 - 14	15 - 21	
Mild +	3	4	24	119	150
Moderate	0	5	26	83	114
Severe	4	15	27	101	147
Profound	33	49	67	112	261
Total	40	73	144	415	672
Total % of all new admissions	1.8%	3.2%	6.4%	18.4%	29.8%

Note: New admissions in this table are children admitted for the first time to individual state institutions. Statistics in this table represent 2253 (79.6%) of the 2831 new admissions to individual state institutions in fiscal year 1991.

Table 31a. Readmissions to State Institutions by Age and Level of Mental Retardation in the Year Ending June 30, 1991

Level of Mental Retardation	Chronological Age				Total
	0 - 4	5 - 9	10 - 14	15 - 21	
Mild +	0	0	5	45	50
Moderate	0	1	7	36	44
Severe	0	2	5	23	30
Profound	1	7	15	29	52
Total	1	10	32	133	176
Total % of all readmissions	.1%	2%	3.3%	13.6%	19.0%

Note: Readmissions in this table are children readmitted to the particular state institutions surveyed. Statistics represent 976 (70.4%) of the 1387 readmissions to individual state institutions in fiscal year 1991.

Table 31b. Discharges from State Institutions by Age and Level of Mental Retardation in the Year Ending June 30, 1991

Level of Mental Retardation	Chronological Age				Total
	0 - 4	5 - 9	10 - 14	15 - 21	
Mild +	4	4	21	140	169
Moderate	0	4	21	95	120
Severe	1	8	18	74	101
Profound	5	34	36	100	175
Total	0	50	96	409	555
Total % of all discharges	.2%	1%	2%	8.6%	11.8%

Note: Discharges in this table are persons discharged from specific state institutions and therefore include some transfers to other state institutions (about 9% of the reported discharges). Statistics in this table represent state institutions with 75.8% of 6276 discharges in fiscal year 1991.

Table source: Lakin, Blake, Prouty, Mangan, & Bruininks (1993), Tables 1.14, 1.15, and 1.16.

Table 32. Characteristics of Residential Treatment Centers (RTCs) for Emotionally Disturbed Children: 1970-1988

HIGHLIGHTS

- The number of RTCs for emotionally disturbed children rose from 261 in 1970 to 368 in 1980, declined to 322 in 1984, then increased substantially to 440 in 1988. Part of this latter increase resulted from the addition to the survey of a universe of RTCs not previously identified. Thus, part of the increase was actual, and part resulted from a more complete coverage of the universe of RTCs. All of these reporting RTCs provided inpatient (i.e., residential treatment) care.

- The number of RTCs providing outpatient services was more than two and a half times greater in 1988 than in 1970, increasing from 48 RTCs in 1970 to 130 in 1988, with only a slight decline occurring between 1980 and 1984. This increase paralleled the increase in total number of reported RTCs. The number of RTCs with partial care service increased from 44 in 1970 to 106 in 1976, decreased to 69 in 1984, then increased again to 156 in 1988.

- Between 1970 and 1980, the number of RTC beds grew from 15,129 to 20,197 before declining to 16,745 beds in 1984. Since 1984, however, RTC beds increased substantially to 25,173 in 1988, primarily as a result of the identification of new organizations.

- Average daily census and year-end resident patients followed a somewhat different pattern from that of additions. Both of these measures reached the 18,000 level in 1979, declined to the 16,000 level in 1983, and then increased to the 23,000 level in 1986 and 1988.

- The pattern of growth in the number of outpatient additions to RTCs between 1969 and 1988 was substantial, but somewhat erratic. From 1969 to 1983, the number of outpatient additions increased four-fold from 7,920 to 32,769. In the three-year period 1983-86, the number almost doubled to 61,855, but since 1986, the outpatient addition count declined to 55,714 in 1988.

- Partial care additions to RTCs increased from 671 in 1969 to 3,431 in 1975, but declined slightly below that level in 1979 and 1983 before increasing again to 8,566 in 1988.

EXPLANATORY NOTES

To be classified as an RTC, an organization must meet all of the following criteria:

- It is an organization, not licensed as a psychiatric hospital, the primary purpose of which is the provision of individually planned programs of mental health treatment services in conjunction with residential care for its patients.

- It has a clinical program within the organization that is directed by a psychiatrist, psychologist, social worker, or psychiatric nurse who has a masters or a doctorate degree.

- It serves children and youth primarily under the age of 18.

- The primary reason for the admission of 50% or more of the children and youth is mental illness that can be classified by DSM-II/ICDA-8 or DSM-III/ICD-9-CM codes, other than those codes for mental retardation, drug-related disorders, and alcoholism.

Table 32. Characteristics of Residential Treatment Centers (RTCs) for Emotionally Disturbed Children: 1970-1988

Characteristic of RTC	1970		1976		1980		1984		1986		1988	
	N	%	N	%	N	%	N	%	N	%	N	%
Number of existing centers	261	8.7	331	9.5	368	9.9	322	7.3	437	9.2	440	8.9
Inpatient/residential treatment services	261	15.1	331	14.6	368	14.6	322	11.3	437	14.4	440	13.6
Outpatient services	48	2.2	57	2.5	68	2.8	63	2.2	99	3.4	130	4.4
Partial care services	44	5.7	106	7.3	104	6.3	69	3.8	123	6.3	156	7.2
Residential treatment beds	15,129	2.9	18,029	5.3	20,197	7.4	16,745	6.4	24,547	9.2	25,173	9.3
	1969		1975		1979		1983		1986		1988	
Residential treatment additions	7.596	.6	12,022	.8	15,453	1.0	16,519	1.0	24,511	1.3	23,441	1.2
Average daily inpatient and residential treatment census	12,406	82.0[1]	16,164	89.7[1]	18,054	89.4[1]	15,826	94.5[1]	22,650	92.3[1]	23,092	91.7[1]
Inpatients and residential treatment residents at end of year	13,469	2.9	16,307	5.7	18,276	7.9	15,791	7.0	23,171	9.7	23,301	10.2
Outpatient additions	7,920	.7	19,784	.9	19,653	.7	32,769	1.2	61,855	2.2	55,714	1.9
Partial care additions	671	1.2	3,431	2.1	2,519	1.5	3,380	1.9	5,489	2.9	8,566	3.1

[1] Percent occupancy

Table source: Redick, Witkin, Atay, & Manderscheid (1992), Tables 1.1 - 1.7.

Data source: Inventory of Mental Health Organizations/Inventory of General Hospital Mental Health Services, 1988

EDUCATION

Table 33. Proportion of Children Ever Treated and Proportion Receiving Special Education for Delays in Growth or Development, Learning Disabilities, and Emotional or Behavior Problems: 1988

HIGHLIGHTS

- Two percent of all children ages 17 years and under had received treatment or counseling for a delay in growth or development. This amounted to 49% of those reported to have had such a delay. One percent of all children were reported to have received treatment for developmental delays within the previous 12 months.

- About 5% of all children ages 3-17 years, or more than three-quarters of those with learning disabilities, had received treatment or counseling for the disabilities. More than 3% of children ages 3-17 years were reported to have received treatment for learning disabilities within the previous 21 months.

- Ten percent of all children ages 3-17 years, or about three-quarters of those with emotional or behavioral problems, had received treatment or counseling for these problems. Five percent were reported to have received this help within the previous 12 months.

- Less than 1% of children ages 6-17 years had received special educational services because of delays in growth or development. This amounted to 22.7% of those reported to have had such delays.

- Of those reported to have learning disabilities, 70% (or 5.5% or all school-aged children) received special educational assistance for their disabilities.

- About 1.7% of school-aged children, or one-quarter of those reported to have emotional or behavioral problems that had lasted 3 months or more, received special educational help because of these problems.

EXPLANATORY NOTES

The data in this table come from the 1988 National Health Interview Survey of Child Health. Parents who reported that their child had a delay in development, a learning disability, or an emotional or behavioral problem were asked whether the child "has ever received treatment or counseling" for the condition. Parents who reported that their child had one of the conditions were also asked whether the condition made it necessary for the child "to attend special classes, or a special school, or get special help at school" during the past 12 months. This question about special educational services was asked only of parents who reported that their child had an emotional or behavioral problem that had lasted 3 months or more.

Table 33. Proportion of Children Ever Treated and Proportion Receiving Special Education for Delays in Growth or Development, Learning Disabilities, and Emotional or Behavior Problems: 1988

Treatment and special education status	Delays in growth or development		Learning disabilities		Emotional or behavioral problems	
	Percent of all children	Percent distribution of all children with condition	Percent of all children	Percent distribution of all children with condition	Percent of all children	Percent distribution of all children with condition
Ever received treatment or counseling for condition	Ages 0 - 17 years		Ages 3 - 17 years		Ages 3 - 17 years	Ages 3 - 17 years[1]
Total	4.0	100.0	6.5	100.0	13.4	100.0
Yes	2.0	49.4	5.1	77.7	10.0	74.5
Within last 12 months	1.1	26.1	3.3	50.3	5.1	38.0
More than 12 months ago	0.9	23.3	1.8	27.4	4.7	35.3
No	2.0	50.6	1.5	22.3	3.4	25.5
Attended special classes or special school in past 12 months because of condition	Ages 6 - 17 years		Ages 6 - 17 years		Ages 6 - 17 years[2]	Ages 6 - 17 years
Total	3.9	100.0	7.8	100.0	6.9	100.0
Yes	0.9	22.7	5.5	69.9	1.7	24.9
No	3.0	77.3	2.3	30.1	5.2	75.1

[1] Includes unknown when treated; excludes unknown whether treated.

[2] Question about receipt of special educational services asked only of those who reported an emotional or behavioral problem that lasted 3 months or longer.

NOTE: Numbers may not add to totals because of rounding

Table source: Zill & Schoenborn (1990), Table 5.

Data source: National Health Interview Survey of Child Health

Table 34. Number and Percent of Students Age 6-21 Served Under IDEA, Part B and Chapter 1 of ESEA (SOP) by Disability: School Year 1991-92

HIGHLIGHTS

- Almost half (49.9%) of all children and youth served under both programs were identified as having specific learning disabilities.

- Other high incidence disabilities included speech or language impairments (22.2%), mental retardation (12.3%), and serious emotional disturbance (8.9%).

- The other disabilities -- multiple disabilities, hearing impairments, orthopedic impairments, other health impairments, visual impairments, deaf-blindness, autism, and traumatic brain injury -- accounted for only 6.7% of all children and youth with disabilities served.

EXPLANATORY NOTES

The Individuals with Disabilities Education Act of 1990 (IDEA), formerly the Education of the Handicapped Act, has the following purposes:

> (1) to provide assistance to states to develop early intervention services for infants and toddlers with disabilities and their families, and to assure a free appropriate public education to all children and youth with disabilities;
>
> (2) to assure that the rights of children and youth with disabilities from birth to age 21 and their families are protected;
>
> (3) to assist states and localities to provide for early intervention services and the education of all children with disabilities; and
>
> (4) to assess and assure the effectiveness of efforts to provide early intervention services and educate children with disabilities.

This table provides national statistics concerning children who received special educational and related services under IDEA and Chapter 1 of the Elementary and Secondary Education Act (ESEA). These data are reported annually by the states to the Office of Special Education Programs (OSEP) in the U.S. Department of Education.

Children ages 5 and younger are not counted by their disability as mandated by P.L. 99-457, the 1986 amendments to the IDEA.

Table 34. Number and Percent of Students Age 6-21 Served Under IDEA, Part B and Chapter 1 of ESEA (SOP) by Disability: School Year 1991-92

Disability	IDEA, Part B		Chapter 1 (SOP)		Total	
	Number	Percent[1]	Number	Percent[1]	Number	Percent[1]
Specific learning disabilities	2,218,948	51.3	30,047	16.6	2,248,995	49.9
Speech or language impairments	990,016	22.9	10,655	5.9	1,000,671	22.2
Mental retardation	500,986	11.6	53,261	29.3	554,247	12.3
Serious emotional disturbance	363,877	8.4	36,793	20.2	400,670	8.9
Multiple disabilities	80,655	1.9	17,747	9.8	98,402	2.2
Hearing impairments	43,690	1.0	17,073	9.4	60,763	1.3
Orthopedic impairments	46,222	1.1	5,468	3.0	51,690	1.1
Other health impairments	56,401	1.3	2,479	1.4	58,880	1.3
Visual impairments	18,296	0.4	5,873	3.2	24,169	0.5
Deaf-blindness	773	0.0	650	0.4	1,423	0.0
Autism	3,555	0.0	1,653	0.9	5,208	0.1
Traumatic brain injury	285	0.0	45	0.0	330	0.0
All disabilities	4,323,704	100.0	181,744	100.0	4,505,448	100.0

[1] Percentages sum within columns.

Table source: Office of Special Education Programs (1993), Table 1.2

Table 35. Number and Percent of Students Age 6-21 Served Under IDEA, Part B and Chapter 1 of ESEA (SOP) by Disability: School Year 1991-92

HIGHLIGHTS

- Compared to the Chapter 1 (SOP) program, the Part B program serves the great majority (96%) of students with disabilities, and it serves more than 98% of all students with specific learning disabilities and speech or language impairments.

- The Part B program also serves most of the students identified as having mental retardation (90%), serious emotional disturbance (91%), orthopedic impairments (89%), other health impairments (96%), and traumatic brain injury (86%).

- The Chapter 1 (SOP) programs, however, served about 20-30% of all students with multiple disabilities, hearing impairments, visual impairments, and autism, and 45% of students with deaf-blindness.

EXPLANATORY NOTES

The Individuals with Disabilities Education Act of 1990 (IDEA), formerly the Education of the Handicapped Act, has the following purposes:

> (1) to provide assistance to states to develop early intervention services for infants and toddlers with disabilities and their families, and to assure a free appropriate public education to all children and youth with disabilities;
>
> (2) to assure that the rights of children and youth with disabilities from birth to age 21 and their families are protected;
>
> (3) to assist states and localities to provide for early intervention services and the education of all children with disabilities; and
>
> (4) to assess and assure the effectiveness of efforts to provide early intervention services and educate children with disabilities.

This table provides national statistics concerning children who received special educational and related services under IDEA and Chapter 1 of the Elementary and Secondary Education Act (ESEA). These data are reported annually by the states to the Office of Special Education Programs (OSEP) in the U.S. Department of Education.

Children ages 5 and younger are not counted by their disability as mandated by P.L. 99-457, the 1986 amendments.

Table 35. Number and Percent of Students Age 6-21 Served Under IDEA, Part B and Chapter 1 of ESEA (SOP) by Disability: School Year 1991-92

Disability	IDEA, Part B		Chapter 1 (SOP)		Total	
	Number	Percent[1]	Number	Percent[1]	Number	Percent[1]
Specific learning disabilities	2,218,948	98.7	30,047	1.3	2,248,995	100.0
Speech or language impairments	990,016	98.9	10,655	1.1	1,000,671	100.0
Mental retardation	500,986	90.4	53,261	9.6	554,247	100.0
Serious emotional disturbance	363,877	90.8	36,793	9.4	400,670	100.0
Multiple disabilities	80,655	82.0	17,747	18.0	98,402	100.0
Hearing impairments	43,690	71.9	17,073	28.1	60,763	100.0
Orthopedic impairments	46,222	89.4	5,468	10.6	51,690	100.0
Other health impairments	56,401	95.8	2,479	4.2	58,880	100.0
Visual impairments	18,296	75.7	5,873	24.3	24,169	100.0
Deaf-blindness	773	54.3	650	45.1	1,423	100.0
Autism	3,555	68.3	1,653	31.7	5,208	100.0
Traumatic brain injury	285	86.4	45	13.6	330	100.0
All disabilities	4,323,704	96.0	181,744	4.0	4,505,448	100.0

[1] Percentages sum across rows.

Table source: Office of Special Education Programs (1993), Table 1.3

Table 36. Percent of Students Age 6-21 Served in Different Educational Environments, by Disability: School Year 1991-92

HIGHLIGHTS

- These data show that 92.8% of students with speech or language impairments and 76.2% of students with specific learning disabilities were served in either regular classes or resource rooms. In contrast, only 23.8% of students with multiple disabilities and 30.4% of students with mental retardation received educational services in these settings. Students with speech or language impairments were the most integrated group of students with 78.9% served in regular class placements, 13.9% served in resource rooms, and only 5.7% in separate classes. The majority (53.7%) of students with specific learning disabilities received educational services in resource rooms. Only 1.1% of students with specific learning disabilities received instruction in separate schools. The most common placements for students with mental retardation were separate classes (53.8%) and resource rooms (23%). Students with serious emotional disturbance were primarily served in separate classes (35.8%) and resource rooms (29.2%).

- Although 46.6% of students with hearing impairments were served in the regular class or resource room placements, the largest single placement category for these students was separate classes (32.7%). An additional 20.1% of students with hearing impairments were served in either separate schools or residential facilities. In contrast, students with visual impairments had the second highest placement rate (42.1%) in regular classes. In addition, 23.2% of these students were served in resource rooms and 19.9% in separate classes.

- About 84% of both students with orthopedic impairments and students with other health impairments received their educational services in regular school (regular class, resource room, and separate class) placements. However, these students were more likely than students with other disabilities to receive services in homebound/hospital settings. Separate class placements (33%) were the most common for students with orthopedic impairments followed closely by regular class placements (29.6%) and resource room placements (22.2%). Similarly, students with other health impairments were fairly evenly distributed among the regular school placements, with 30.2% served in regular classes, 27.7% in resource rooms, and 26.2% in separate classes.

- Students with deaf-blindness were most likely to receive educational services in residential facilities (25.2%) and separate classrooms (32.3%). Relatively large percentages of these students were also served in separate schools. The most common placements for students with multiple disabilities were separate classes (42.8%) and separate school facilities (27.7%).

EXPLANATORY NOTES

This table provides national statistics concerning children who received special educational and related services under IDEA and Chapter 1 of the Elementary and Secondary Education Act (ESEA). These data are reported annually by the states to the Office of Special Education Programs (OSEP) in the U.S. Department of Education. Children ages 5 and younger are not counted by their disability as mandated by P.L. 99-457, the 1986 amendments. IDEA and implementing regulations require that each student have an individualized education program (IEP) that defines appropriate educational services. An educational placement, selected from a continuum of alternatives, provides services in the setting that meets each students' educational needs and offers the greatest opportunity for interaction with students who do not have disabilities.

Table 36. Percent of Students Age 6-21 Served in Different Educational Environments, by Disability: School Year 1991-92

Disability	Regular Class	Resource Room	Separate Class	Separate School	Residential Facility	Homebound/ Hospital
Specific learning disabilities	22.5	53.7	22.4	1.1	0.1	0.2
Speech or language impairments	78.9	13.9	5.7	1.4	0.1	0.2
Mental retardation	7.4	23.0	58.3	9.8	1.1	0.4
Serious emotional disturbance	16.8	29.2	35.8	13.3	3.5	1.5
Hearing impairments	26.9	19.7	32.7	9.1	11.0	0.5
Multiple disabilities	6.6	17.2	42.8	27.7	3.5	2.1
Orthopedic impairments	29.6	22.2	33.0	8.9	0.7	5.6
Other health impairments	30.2	27.7	26.2	7.3	1.0	7.6
Visual impairments	42.1	23.2	19.9	5.0	8.8	1.0
Deaf-blindness	10.5	6.4	32.3	23.5	25.2	2.2
All disabilities	32.8	36.5	25.1	4.2	0.8	0.6

Table source: Office of Special Education Programs (1993), Table 1.6

Regular class includes students who receive the majority of their education program in a regular classroom and receive special education and related services outside the regular classroom for less than 21% of the school day. It includes children placed in a regular class and receiving special education within the regular class, as well as children placed in a regular class and receiving special education outside the regular class.

Resource room includes students who receive special education and related services outside the regular classroom for at least 21% but no more than 60% of the school day. This may include students placed in resource rooms with part-time instruction in a regular class.

Separate class includes students who receive special education and related services outside the regular classroom for more than 60% of the school day. Students may be placed in self-contained special classrooms with part-time instruction in regular classes or placed in self-contained classes full-time on a regular school campus.

Separate school includes students who receive special education and related services in separate day schools for students with disabilities for more than 50% of the school day.

Residential facility includes students who receive education in a public or private residential facility, at public expense, for more than 50% of the school day.

Homebound/hospital environment includes students placed in and receiving special education in hospital or homebound programs.

Table 37. Number and Percent of Students Enrolled in Special Education Programs, by Ethnicity and Sex: 1990

HIGHLIGHTS

- Children with specific learning disabilities comprised the largest enrollment in special education classes. Nearly 2 million children with learning disabilities were estimated to be enrolled in special education classes as of October 1, 1990. The smallest proportion of special education students were those identified as trainable mentally retarded.

- Boys were more likely to be enrolled in special education programs than were girls. The largest difference was in estimated enrollment for children who were seriously emotionally disturbed, where boys outnumbered girls 8 to 2.

- Distribution of students by race was fairly constant across programs, with two exceptions. Hispanic children represent 20% of the estimated total enrollment in trainable mentally retarded programs, which is higher than their representation in other program categories. Black children comprise one-third of enrollment in both categories of mental retardation, yet less than one-fourth of the enrollment of children with speech impairments, serious emotional disturbance, and learning disabilities.

EXPLANATORY NOTES

This table presents adjusted national estimated data using the 1990 Elementary and Secondary School Civil Rights Survey. The survey is conducted every two years and results are used by the Office of Civil Rights (OCR), U.S. Department of Education, to ensure compliance with civil rights laws that prohibit discrimination on the basis of race, national origin, handicap, sex, and age. Student information was reported as of October 1, 1990.

Adjusted national estimates were developed using weighted data from a stratified random sample. Each of the six strata had a statistical weight based on the initial sample design. This weight was used to produce estimates of national totals for each of the survey variables. Racial/ethnic and gender components of the estimates were further adjusted based on the reported totals.

The categories of educable mentally retarded, trainable mentally retarded, speech impaired, seriously emotionally disturbed, and specific learning disability were the only categories for which information was collected by race and sex.

Table 37. Number and Percent of Students Enrolled in Special Education Programs, by Ethnicity and Sex: 1990

Program	Ethnicity					Total	Sex	
	American Indian	Asian	Hispanic	Black	White		Male	Female
Educable mentally retarded	4,199	3,605	30,479	138,963	223,953	401,199	235,344	165,855
Percent of total	1	1	8	35	56		59	41
Trainable mentally retarded	938	3,281	29,649	47,253	68,532	149,653	93,016	56,637
Percent of total	1	2	20	32	46		62	38
Speech impaired	11,394	19,557	92,100	171,540	780,244	1,074,835	686,284	388,551
Percent of total	1	2	9	16	73		64	36
Seriously emotionally disturbed	2,793	1,813	15,733	59,190	191,468	270,998	215,453	55,545
Percent of total	1	1	6	22	71		80	20
Specific learning disability	24,745	22,037	220,703	327,799	1,377,845	1,973,129	1,378,170	594,959
Percent of total	1	1	11	17	70		70	30

Table source: Office for Civil Rights (1993).

Data source: 1990 Elementary and Secondary School Civil Rights Survey

Educable mentally retarded is a condition of mental retardation which includes pupils who are educable in the academic, social, and occupational areas even though moderate supervision may be necessary.

Trainable mentally retarded is a condition of mental retardation which includes pupils who are capable of only very limited meaningful achievement in the traditional basic academic skills but who are capable of profiting from programs of training in self-care and simple job or vocational skills.

Speech impaired is a communication disorder, such as stuttering, impaired articulation, a language impairment, or a voice impairment, which adversely affects a child's educational performance.

Seriously emotionally disturbed is a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree, which adversely affect educational performance: an inability to learn which cannot be explained by intellectual, sensory, or health factors; an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; inappropriate types of behavior or feelings under normal circumstances; a general pervasive mood of unhappiness or depression, or a tendency to develop physical symptoms or fears associated with personal or school problems. The term includes children who are schizophrenic.

Specific learning disability is a disorder in one or more of the basic psychological processes involved in understanding or in using language, spoken or written, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or to do mathematical calculations. The term includes such conditions as perceptual handicaps, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia. The term does not include children who have learning problems which are primarily the result of visual, hearing, and motor handicaps, of mental retardation, or of environmental, cultural, or economic disadvantage.

Table 38. Enrollment in Special Education by Amount of Time Participating: 1990

HIGHLIGHTS

- Half of the estimated enrollment in special education are children with learning disabilities. One-quarter of the students are hearing impaired. The other categories of disability each account for 10% or less of the total enrollment in special education.

- Enrollment by full-time and part-time status varied widely among program categories. Overall, 76% of students attend programs part-time. Students with speech impairments are most likely to be enrolled on a part-time basis (93%), while students with trainable mental retardation are most likely to be in full-time programs (85%).

EXPLANATORY NOTES

This table presents adjusted national estimated data using the 1990 Elementary and Secondary School Civil Rights Survey. The survey is conducted every two years and results are used by the Office of Civil Rights (OCR), U.S. Department of Education, to ensure compliance with civil rights laws that prohibit discrimination on the basis of race, national origin, handicap, sex, and age. Student information was reported as of October 1, 1990.

Adjusted national estimates were developed using weighted data from a stratified random sample. Each of the six strata had a statistical weight based on the initial sample design. This weight was used to produce estimates of national totals for each of the survey variables. Racial/ethnic and gender components of the estimates were further adjusted based on the reported totals.

Table 38. Enrollment in Special Education by Amount of Time Participating: 1990

Program	Enrollment		Part Time		Full Time	
	Number	Percent of total	Number	Percent	Number	Percent
Educable mentally retarded	401,199	10	179,149	45	222,050	55
Trainable mentally retarded	149,653	4	22,551	15	127,102	85
Hard of hearing	31,059	1	22,634	73	8,425	27
Deaf	14,157	0	5,674	40	8,483	60
Speech impaired	1,074,835	26	995,631	93	79,204	7
Visually impaired	18,319	0	12,770	70	5,549	30
Seriously emotionally disturbed	270,998	7	158,161	58	112,837	42
Orthopedically impaired	44,721	1	24,908	56	19,813	44
Other health impaired	52,323	1	35,954	69	16,369	31
Specific learning disability	1,973,129	49	1,601,561	81	371,568	19
Deaf-blind	1,249	0	481	39	768	61
Multihandicapped	86,378	2	20,704	24	65,024	75
Total	4,057,253	100	3,074,032	76	974,689	24

Table Source: Office for Civil Rights (1993).

Data source: 1990 Elementary and Secondary School Civil Rights Survey

Table 39. Distribution of Children in Head Start Who Have One or More Disabling Conditions, by Primary or Most Disabling Conditions: 1989-90

HIGHLIGHTS

- Head Start serves a significant proportion of children with severe or multiple disabilities. In 1990, there were 10,780 (15.5%) children with disabilities enrolled in Head Start programs who had multiple disabling conditions.

- The highest incidence of multiple disabling conditions occurred among children whose primary disabling condition is deafness (52.2%) and mental retardation (59.4%). Speech impaired children showed the lowest incidence of multiple disabilities (8.5%).

EXPLANATORY NOTES

This table is based on data from Head Start Program Information Reports (PIR) which were completed by Head Start programs as of June 30, 1990 and cover program year 1989-90. In the 1989-90 program year, Head Start provided developmental services to 521,266 children. Of these, the number of children with disabilities served was 69,267, or 13.3% of total enrollment. The data come from 1321 Head Start full year programs.

Head Start is mandated to serve children with a broad range of disabilities such as those who are mentally retarded, hard of hearing, deaf, speech impaired, visually disabled, seriously emotionally disturbed, or orthopedically impaired. Also included are children with health impairments, or children with specific learning disabilities who require special education and related services.

The statutory definition of children with disabilities excludes from reporting as disabled those children with correctable conditions who do not need special services, or children who will not require services in addition to those which Head Start programs regularly provide. In order to meet this reporting requirement and to ensure that children who are considered disabled are not misdiagnosed, Head Start requires that each child reported as disabled be diagnosed by appropriate professionals.

Table 39. Distribution of Children in Head Start Who Have One or More Disabling Conditions, by Primary or Most Disabling Conditions: 1989-90

Disabling Condition	Total Number of Children	Number of Children with Other Disabling Conditions	Percent with Multiple Disabling Conditions
Blindness	95	37	39.0
Visual Impairment	1,244	265	21.3
Deafness	90	47	52.2
Hearing Impairment	1,331	512	38.5
Physical Disability	2,724	871	32.0
Speech Impairment	46,549	3,957	8.5
Health Impairment	7,611	1,372	18.0
Mental Retardation	2,616	1,553	59.4
Emotional Disturbance	2,898	743	26.0
Learning Disability	4,109	1,423	34.6
Total	69,267	10,780	15.6

Table source: Head Start Bureau (1992), Table 3.

Data source: Head Start Program Information Reports, 1989-90

Table 40. Children Receiving Special Education or Related Services from Head Start Only, Other Agencies Only, or Both: 1989-90

HIGHLIGHTS

- In 1989-90, 35.1% of children with disabilities served received special education or related services from Head Start only; 5.3% received such services from another agency only; and 59.6% received special services from both Head Start and another agency.

EXPLANATORY NOTES

This table is based on data from Head Start Program Information Reports (PIR) which were completed by Head Start programs as of June 30, 1990 and cover program year 1989-90. In the 1989-90 program year, Head Start provided developmental services to 521,266 children. Of these, the number of children with disabilities served was 69,267, or 13.3% of total enrollment. The data come from 1,321 Head Start full year programs.

Head Start is mandated to serve children with a broad range of disabilities such as those who are mentally retarded, hard of hearing, deaf, speech impaired, visually disabled, seriously emotionally disturbed, or orthopedically impaired. Also included are children with health impairments, or children with specific learning disabilities who require special education and related services.

The statutory definition of children with disabilities excludes from reporting as disabled those children with correctable conditions who do not need special services, or children who will not require services in addition to those which Head Start programs regularly provide. In order to meet this reporting requirement and to ensure that children who are considered disabled are not misdiagnosed, Head Start requires that each child reported as disabled be diagnosed by appropriate professionals.

Services provided for children with disabilities through other agencies include: psychological and physical therapy; medical or psychological diagnosis; evaluation or testing; individualized teaching techniques; education in diet, food, health and nutrition; assistance in obtaining special services included in the individualized education program; special teaching equipment; psychotherapy, counseling, and behavioral management; medical treatment; special equipment for children; physiotherapy; and occupational therapy.

Table 40. Children Receiving Special Education or Related Services from Head Start Only, Other Agencies Only, or Both: 1989-90

Primary Disabling Conditions	Head Start Only	Other Agencies Only	Both Head Start and Other Agencies
Blindness	9	6	80
Visual Impairment	350	110	784
Deafness	9	3	78
Hearing Impairment	296	65	970
Physical Disability	542	180	2,002
Speech Impairment	18,014	2,400	26,135
Health Impairment	2,349	489	4,773
Mental Retardation	666	69	1,881
Emotional Disturbance	817	197	1,884
Learning Disability	1,279	163	2,667
Total	24,331 (35%)	3,682 (5%)	41,254 (60%)

Table source: Head Start Bureau (1992), Table 5.

Data source: Head Start Program Information Reports

Table 41. Distribution of Separate Day School Students by Type and Severity of Primary Disability: 1987-88

HIGHLIGHTS

- The largest category of day school students were those with mental retardation (39.2%). Within this category, 5.1% of all day school students had mild mental retardation, 15% had moderate mental retardation, 11.2% had severe mental retardation, and 7.9% had profound mental retardation. In addition, 6.4% of students in separate day school were reported to have multiple impairments with mild or moderate mental retardation as one of their conditions, and 76.9% of students were reported to have multiple impairments with severe or profound mental retardation as one of their conditions.

- Nearly half (47.6%) of the estimated 19% of day school students reported as emotionally disturbed were classified as having serious conduct or behavior disorders.

- Students with learning disabilities comprised an estimated 8.9% of students in separate day schools.

EXPLANATORY NOTES

Data for this table were collected as part of the Study of Programs of Instruction for Handicapped Children and Youth in Day and Residential Facilities conducted for the 1987-88 school year. This national study was sponsored by the Office of Special Education Programs (OSEP) to collect detailed information on separate day and residential facilities, the students served, the environment in which they operate, and the services they provide. These institutions serve about 7% of all students with disabilities.

A separate facility was defined as a residential or day facility exclusively serving persons with disabilities in buildings physically separate from programs for non-disabled age peers. A separate day school or facility was further defined as a separate facility at which no persons with disabilities reside and at which students birth to age 22 receive educational services during the usual school day.

Data for this table come from 96,025 of the 136,593 students (unweighted) with disabilities in schools who comprised the day school sample.

Table 41. Distribution of Separate Day School Students by Type and Severity of Primary Disability: 1987-88

Type and Severity of Primary Disability	Estimated Total Students	Students with Primary Conditions	Students in Public Facilities[1]	Students in Private Facilities[1]	Total Day School Students Age 0-21[2]
Learning disabilities	20,124				
Mild/moderate		59.9%	28.8%	71.2%	5.3%
Severe		37.2	37.3	62.7	3.3
Other		2.9	17.5	82.5	0.3
Mental retardation	89,156				
Mild		13.0	71.3	28.7	5.1
Moderate		38.4	84.5	15.5	15.0
Severe		28.6	86.5	13.5	11.2
Profound		20.1	86.8	13.2	7.9
Emotional disturbance	44,185				
Attention deficit disorder		17.4	52.3	47.7	3.4
Serious conduct/behavior disorder		47.6	67.4	32.6	9.2
Anxiety or withdrawal disorder		9.8	52.7	47.3	1.9
Pervasive developmental disorder		5.8	51.6	48.4	1.1
Substance abuse or dependence		3.1	57.1	42.9	0.6
Psychotic or schizophrenic disorders		7.2	59.9	40.1	1.4
Other		9.2	58.0	42.0	1.8
Hearing impairments	4,556				
Prelingually deaf, mild		5.1	*	*	0.1
Prelingually deaf, moderate		14.0	*	*	0.3
Prelingually deaf, severe		72.9	61.2	38.8	1.5
Postlingually deaf, mild		0.2	*	*	<0.1
Postlingually deaf, moderate		1.1	*	*	<0.1
Postlingually deaf, severe		6.7	*	*	0.1
Visual impairments	1,189				
Functionally blind		35.9	*	*	0.2
Legally blind		35.9	*	*	0.2
Partially sighted		28.3	*	*	0.1
Orthopedic/physical impairments	12,231				
Cerebral palsy		55.6	61.4	38.6	3.0
Quadriplegia, paraplegia, hemiplegia		8.2	70.8	29.2	0.4
Missing/deformed limbs		1.6	*	*	0.1
Other nervous or musculoskeletal system		34.5	55.7	44.3	1.8
Health impairments	3,489				
Respiratory		27.4	47.2	52.8	0.3
Circulatory		4.2	*	*	0.1
Other		68.4	69.3	30.7	1.0
Autism	5,707	100.0	66.1	33.9	2.5
Speech/language impairments	7,869				
Speech impaired		53.0	65.1	34.9	1.8
Language impaired		47.0	50.6	49.4	1.6
Multiple impairments	32,749				
With mild/moderate retardation		45.2	78.4	21.6	6.4
With severe/profound retardation		48.1	72.2	27.8	6.9
Without mental retardation		6.7	41.8	58.2	1.0
Deaf-blind	149	100.0	*	*	<0.1
Non-categorical	7,312	100.0	45.4	54.6	3.2
Total	228,716	100.0	69.8	30.2	100.0

[1] These two percentages will sum to 100% within the row.

[2] These percentages will sum to 100% within the column.

*Indicates estimates for which sample size is insufficient to permit reliable statistical inference.

Table source: Stephens, Lakin, Brauen, & O'Reilly (1990), Table 3.9; Data source: Study of Programs of Instruction for Handicapped Children and Youth in Day and Residential Facilities

Table 42. Distribution of Separate Residential School Students by Type and Severity of Primary Disability: 1987-88

HIGHLIGHTS

- The largest group of residential facility students were those with emotional disturbance (51.8%). An estimated 22.6% of all residential school students were reported to have conduct or behavior disorders, as compared with 18% of residential school students reported to have mental retardation.
- Nearly 11% of all residential school students had hearing impairments as a primary disabling condition, with 85.5% of these students having severe prelingual deafness.
- Students with learning disabilities comprised only 3.8% of the residential school students.

EXPLANATORY NOTES

Data for this table were collected as part of the 1987-88 Study of Programs of Instruction for Handicapped Children and Youth in Day and Residential Facilities. This national study was sponsored by the Office of Special Education Programs (OSEP) to collect detailed information on separate day and residential facilities, the students served, the environment in which they operate, and the services they provide. These institutions serve about 7% of all students with disabilities.

A separate facility was defined as a residential or day facility exclusively serving persons with disabilities in buildings physically separate from programs for non-disabled age peers. A residential separate facility was further defined as a separate facility at which at least some persons with disabilities reside and at which at least some students birth to age 22 receive educational services on the grounds of the facility during the usual school day.

Data for this table come from 39,355 or the 56,626 students (unweighted) with disabilities in schools who comprise the residential school sample.

Table 42. Distribution of Separate Residential School Students by Type and Severity of Primary Disability: 1987-88

Type and Severity of Primary Disability	Estimated Total Students	Students with Primary Conditions	Students in Public Facilities[1]	Students in Private Facilities[1]	Total Day School Students Age 0-21[2]
Learning disabilities	3,685				
Mild/moderate		55.1%	10.2%	89.8%	2.1%
Severe		44.2	3.4	96.6	1.7
Other		0.6	*	*	<0.1
Mental retardation	17,171				
Mild		12.0	37.9	62.1	2.2
Moderate		15.2	37.9	62.1	2.7
Severe		23.2	55.9	44.1	4.2
Profound		49.6	69.8	30.2	8.9
Emotional disturbance	49,277				
Attention deficit disorder		19.1	29.9	70.1	9.9
Serious conduct/behavior disorder		43.7	25.8	74.2	22.6
Anxiety or withdrawal disorder		9.6	25.5	74.5	5.0
Pervasive developmental disorder		4.4	32.5	67.5	2.3
Substance abuse or dependence		6.4	16.2	83.8	3.3
Psychotic or schizophrenic disorders		6.5	36.5	63.5	3.4
Other		10.3	30.8	69.2	5.3
Hearing impairments	10,179				
Prelingually deaf, mild		1.6	*	*	0.2
Prelingually deaf, moderate		6.3	*	*	0.6
Prelingually deaf, severe		85.5	71.6	28.4	9.1
Postlingually deaf, mild		0.4	*	*	<0.1
Postlingually deaf, moderate		1.2	*	*	0.1
Postlingually deaf, severe		5.1	*	*	0.5
Visual impairments	2,740				
Functionally blind		39.1	97.7	2.3	1.1
Legally blind		50.3	96.8	3.2	1.4
Partially sighted		10.6	*	*	0.3
Orthopedic/physical impairments	1,283				
Cerebral palsy		52.5	*	*	0.7
Quadriplegia, paraplegia, hemiplegia		8.8	*	*	0.1
Missing/deformed limbs		3.2	*	*	<0.1
Other nervous or musculoskeletal system		35.5	*	*	0.5
Health impairments	395				
Respiratory		*	*	*	<0.1
Circulatory		*	*	*	<0.1
Other		*	*	*	0.4
Autism	2,451	100.0	17.4	82.6	2.6
Speech/language impairments	682				
Speech impaired		*	*	*	0.5
Language impaired		*	*	*	0.3
Multiple impairments	6,748				
With mild/moderate retardation		31.6	31.6	68.4	2.2
With severe/profound retardation		42.2	49.8	50.2	3.0
Without mental retardation		26.6	35.4	64.6	1.9
Deaf-blind	170	100.0	*	*	0.2
Non-categorical	554	100.0	*	*	0.6
Total	95,335	100.0	38.6	61.4	100.0

[1] These two percentages will sum to 100% within the row.

[2] These percentages will sum to 100% within the column.

*Indicates estimates for which sample size is insufficient to permit reliable statistical inference.

Table source: Stephens, Lakin, Brauen, & O'Reilly (1990), Table 3.10; Data source: Study of Programs of Instruction for Handicapped Children and Youth in Day and Residential Facilities

Table 43. Number and Percentage of Hearing Impaired Children and Youth, Regional and National Summary: 1992-93

HIGHLIGHTS

- The number of children reported to the Annual Survey of Deaf and Hard of Hearing Children and Youth was 48,300. Of these children, 54% were boys and 45.8% were girls. Most of the students were ages 6 through 17. The greatest concentration of Hispanic students was in the Western region (32.5%) and the greatest concentration of black students was in the South (27.2%).

- Information on age at onset of hearing loss was reported for 67% of children. Of these children, 71% had hearing loss at birth. Probable cause of hearing loss at birth was not reported for 52.6% of children. Of the 47.4% for whom information was reported, 27.6% cited heredity as the probable cause of hearing loss. Age at onset of loss should not be confused with age at identification of loss.

- Over one-third (37.6%) of the children reported to the survey have profound hearing loss (a hearing threshold of 91dB or higher).

- The primary methods of teaching hearing impaired children is sign and speech (56.1%) and auditory (41.1%). In most educational settings, an interpreter is not provided (53.2%) and the teacher communicates for him or herself (29.3%). Only 16.7% of schools provided a sign interpreter. Nearly all (94.2%) of the children reported to the survey had received special education classroom instruction. Most students (65.8%) received their education in a regular education facility for hearing students and 20.6% were in residential schools for deaf students.

- Over half of the students (55.6%) had at least 1 hour of academic classroom integration with hearing students. The largest proportion (34.3%) had 16 or more hours of integration. However, 44.4% of students had no classroom integration with hearing students.

EXPLANATORY NOTES

Data in this table come from the Annual Survey of Deaf and Hard of Hearing Children and Youth conducted by the Center for Assessment and Demographic Studies (CADS) at Gallaudet University. The survey is mailed annually to all special educational programs enrolling deaf and hard-of-hearing students. Since the survey is voluntary, the data reported to the survey do not include all hearing-impaired students receiving special education services. CADS estimates that its survey represents about 60% of deaf and hard-of-hearing children receiving special education services.

Table 43. Number and Percentage of Hearing Impaired Children and Youth, Regional and National Summary: 1992-93

	Northeast		Midwest		South		West		Nation	
	N	%	N	%	N	%	N	%	N	%
Total students	9044	100.0	12155	100.0	17550	100.0	9551	100.0	48300	100.0
Age										
Under 3 years	172	1.9	206	1.7	703	4.1	162	1.7	1243	2.6
From 3 to 5 years	974	11.0	1241	10.4	2033	11.7	947	10.1	5195	10.9
From 6 to 9 years	2134	24.0	3061	25.6	3975	23.0	2369	25.1	11539	24.2
From 10 to 13 years	2585	29.1	3483	29.1	4608	26.6	2757	29.3	13433	28.2
From 14 to 17 years	2151	24.2	2944	24.6	4325	25.0	2425	25.7	11845	24.9
18 years and older	875	9.8	1030	8.6	1670	9.6	761	8.1	4336	9.1
Information not reported	153	1.7	190	1.6	236	1.3	130	1.4	709	1.5
Sex										
Male	4899	54.2	6575	54.1	9412	53.6	5158	54.0	26044	53.9
Female	4115	45.5	5547	45.6	8093	46.1	4366	45.7	22121	45.8
Ethnic origin										
White, non-Hispanic	5354	60.7	9156	75.9	9691	55.8	4552	48.5	28753	60.4
Black, non-Hispanic	1374	15.6	1682	13.9	4712	27.2	612	6.5	8380	17.6
Hispanic	1598	18.1	552	4.6	2319	13.4	3054	32.5	7523	15.8
American Indian	6	0.1	85	0.7	69	0.4	161	1.7	321	0.7
Asian/Pacific	277	3.1	408	3.4	309	1.8	779	8.3	1773	3.7
Other	176	2.0	130	1.1	182	1.0	147	1.6	635	1.3
Multi-ethnic background	36	0.4	58	0.5	70	0.4	86	0.9	250	0.5
Age at onset of hearing loss										
At birth	4261	71.6	5992	74.7	8204	66.9	4391	74.0	22848	71.0
Under 3 years	1303	21.9	1583	19.7	3336	27.2	1184	20.0	7406	23.0
3 years or older	386	6.5	451	5.6	723	5.9	359	6.0	1919	6.0
Information not reported	3094	34.2	4129	34.0	5287	30.1	3617	37.9	16127	33.4
Probable Cause of Hearing Loss										
At Birth										
Information not reported	5051	55.8	6421	52.8	8522	48.6	5413	56.7	25407	52.6
Maternal rubella	228	5.7	217	3.8	379	4.2	168	4.1	992	4.3
Trauma at birth	233	5.8	260	4.5	460	5.1	223	5.4	1176	5.1
Other complications of pregnancy	243	6.1	267	4.7	442	4.9	185	4.5	1137	5.0
Heredity	1263	31.6	1778	31.0	2204	24.4	1079	26.1	6324	27.6
Prematurity	324	8.1	543	9.5	967	10.7	404	9.8	2238	9.8
Cytomegalovirus	93	2.3	142	2.5	313	3.5	90	2.2	638	2.8
RH incompatibility	18	0.5	41	0.7	89	1.0	31	0.7	179	0.8
Other cause at birth	342	8.6	585	10.2	910	10.1	546	13.2	2383	10.4
After birth										
Meningitis	567	14.2	949	16.6	1770	19.6	648	15.7	3934	17.2
High fever	152	3.8	197	3.4	556	6.2	222	5.4	1127	4.9
Mumps	2	0.1	4	0.1	10	0.1	6	0.1	22	0.1
Infection	175	4.4	228	4.0	443	4.9	216	5.2	1062	4.6
Measles	13	0.3	30	0.5	57	0.6	32	0.8	132	0.6
Otitis media	326	8.2	577	10.1	577	6.4	302	7.3	1782	7.8
Trauma after birth	77	1.9	67	1.2	119	1.3	77	1.9	340	1.5
Other cause after birth	179	4.5	255	4.4	500	5.5	190	4.6	1124	4.9

Table 43. Number and Percentage of Hearing Impaired Children and Youth, Regional and National Summary: 1992-93

	Northeast		Midwest		South		West		Nation	
	N	%	N	%	N	%	N	%	N	%
Additional disabling condition										
Legal blindness	110	1.2	142	1.2	252	1.5	145	1.6	649	1.4
Uncorrected visual problem	388	4.4	407	3.4	605	3.5	465	5.1	1865	4.0
Brain damage or injury	146	1.6	100	0.8	175	1.0	107	1.2	528	1.1
Epilepsy	86	1.0	135	1.1	195	1.1	100	1.1	516	1.1
Orthopedic	223	2.5	300	2.5	445	2.6	241	2.6	1209	2.6
Cerebral palsy	214	2.4	330	2.8	527	3.1	300	3.3	1371	2.9
Heart disorder	132	1.5	130	1.1	153	0.9	125	1.4	540	1.1
Other health impaired	361	4.1	434	3.6	668	3.9	382	4.2	1845	3.9
Mental retardation	693	7.8	994	8.4	1519	8.9	556	6.1	3762	8.0
Emotional or behavioral problem	504	5.7	425	3.6	618	3.6	339	3.7	1886	4.0
Specific learning disability	1229	13.8	995	8.4	1073	6.3	901	9.9	4198	8.9
Attention Deficit Disorder	101	1.1	169	1.4	199	1.2	71	0.8	540	1.1
Other	182	2.0	349	2.9	483	2.8	260	2.9	1274	2.7
Primary Method of Teaching										
Auditory/oral only	4378	48.9	5458	45.3	5819	33.7	3950	41.7	19605	41.1
Sign and speech	4335	48.4	6149	51.0	11019	63.9	5245	55.4	26748	56.1
Sign only	191	2.1	372	3.1	181	1.0	176	1.9	920	1.9
Cued speech	15	0.2	23	0.2	151	0.9	46	0.5	235	0.5
Other	29	0.3	48	0.4	83	0.5	45	0.5	205	0.4
Interpreter Provided										
Sign interpreter provided	865	10.0	2063	17.6	3341	19.9	1483	16.3	7752	16.7
Oral interpreter provided	38	0.4	59	0.5	63	0.4	61	0.7	221	0.5
Cued speech interpreter	19	0.2	18	0.2	72	0.4	20	0.2	129	0.3
Interpreter not provided	5147	59.7	6601	56.2	8302	49.3	4559	50.2	24609	53.2
Teacher communicates for self	2558	29.7	3011	25.6	5047	30.0	2963	32.6	13579	29.3
Cochlear Implant										
Have had a cochlear implant	75	1.5	247	3.1	265	2.2	76	1.3	663	2.2
Had not had a cochlear implant	5038	98.5	7616	96.9	11586	97.8	5820	98.7	30060	97.8
Information not reported	3931	43.5	4292	35.3	5699	32.5	3655	38.3	17577	36.4
Degree of Hearing Loss										
Normal	898	10.2	1455	12.2	1204	7.0	1051	11.6	4608	9.8
Mild	973	11.0	1420	11.9	1431	8.4	971	10.7	4795	10.2
Moderate	1067	12.1	1620	13.6	1976	11.6	1157	12.7	5820	12.4
Mod. severe	998	11.3	1523	12.8	2145	12.5	1108	12.2	5774	12.3
Severe	1429	16.2	1965	16.5	3403	19.9	1525	16.8	8322	17.7
Profound	3463	39.2	3952	33.1	6948	40.6	3271	36.0	17634	37.6
Fluctuating Hearing Loss										
Have fluctuating hearing loss	594	8.7	924	9.8	539	5.4	490	7.1	2547	7.7
No fluctuating hearing loss	6270	91.3	8523	90.2	9375	94.6	6369	92.9	30537	92.3
Information not reported	2180	24.1	2708	22.3	7636	43.5	2692	28.2	15216	31.5
Unilateral hearing loss										
Have unilateral hearing loss	537	7.8	640	6.7	608	6.1	424	6.1	2209	6.6
No unilateral hearing loss	6379	92.2	8857	93.3	9327	93.9	6478	93.9	31041	93.4
Information not reported	2128	23.5	2658	21.9	7615	43.4	2649	27.7	15050	31.2

Table 43. Number and Percentage of Hearing Impaired Children and Youth, Regional and National Summary: 1992-93

	Northeast		Midwest		South		West		Nation	
	N	%	N	%	N	%	N	%	N	%
Special Education Classroom Instruction Received										
Instruction received	8474	94.6	11192	92.5	16515	95.3	8885	93.8	45066	94.2
Instruction not received	482	5.4	911	7.5	809	4.7	588	6.2	2790	5.8
Type of Facility										
Residential school for deaf	1672	18.8	1988	16.5	4335	24.9	1860	19.7	9855	20.6
Day school for the deaf	1818	20.4	261	2.2	772	4.4	917	9.7	3768	7.9
Regular education facility for hearing students	4820	54.2	9099	75.6	11380	65.5	6136	65.0	31435	65.8
Other	532	6.0	655	5.4	824	4.7	521	5.5	2532	5.3
Speech and hearing clinic/center	51	0.6	27	0.2	67	0.4	4	0.0	149	0.3
Hours per Week Integration With Hearing Students										
None	4407	49.1	4794	39.8	7795	45.5	4170	44.1	21166	44.4
1 to 4 hours per week	466	5.2	1202	10.0	2036	11.9	964	10.2	4668	9.8
5 to 10 hours per week	440	4.9	715	5.9	1129	6.6	612	6.5	2896	6.1
11 to 15 hours per week	271	3.0	920	7.6	896	5.2	477	5.0	2564	5.4
16 or more hours per week	3386	37.7	4424	36.7	5283	30.8	3233	34.2	16326	34.3

Table source: Center for Assessment and Demographic Studies (1993).

Data source: Annual Survey of Deaf and Hard of Hearing Children and Youth

Table 44. Percentage of Disabled Undergraduates and Type of Disability, by Selected Student and Institution Characteristics: Academic Year 1989-90

HIGHLIGHTS

- Overall, 7% of undergraduates reported that they had some type of disability. White students were more likely to report having a disability (7%) than were Black, Hispanic, or Asian students (5%, 4%, and 3%, respectively).

- Disability status was also related to the educational objectives of undergraduates. Seven percent of students aspiring to earn a bachelor's or an advanced degree had some type of disability compared with 11% of those intending to complete some college but less than a bachelor's degree, and 16% of those intending to obtain vocational training requiring less than 2 years of school. Even though about 13% of undergraduates intending to obtain vocational-technical degrees requiring 2 or more years were disabled, their small sample precluded finding a difference between these students and disabled students seeking baccalaureate or advanced degrees.

Explanatory Notes

Data for this table come from the National Postsecondary Student Aid Study for the academic year 1989-90. The data on disability status is self-reported. Some students may have overreported or underreported their physical conditions.

Table 44. Percentage of Disabled Undergraduates and Type of Disability, by Selected Student and Institution Characteristics: Academic Year 1989-90.

	Percent Disabled	Type of disability among disabled				
		Hearing*	Speech*	Learning	Mobility	Other
Total	6.6	34.6	4.5	20.2	36.3	22.7
Sex						
Male	8.1	34.9	5.3	23.2	35.3	21.0
Female	5.8	34.3	3.6	16.9	37.6	24.6
Ethnicity						
American Indian	12.4	–	–	–	–	–
Asian	3.4	40.8	21.9	14.2	26.9	26.1
Black, non-Hispanic	5.2	27.4	10.3	22.7	30.8	36.6
Hispanic	3.7	33.7	6.6	14.9	41.3	17.8
White, non-Hispanic	7.2	34.7	3.4	20.3	37.0	21.4
Dependency status						
Dependent	4.6	31.7	4.3	29.4	25.8	18.5
Independent	8.5	36.0	4.6	15.6	41.6	24.7
Educational Objective						
Voc-tech, less than 2 years	15.6	35.7	1.9	26.3	39.6	19.3
Voc-tech, 2 or more years	12.7	43.2	2.8	26.0	24.9	29.8
Some college	10.8	32.1	7.8	19.2	39.7	31.0
Bachelor's degree	7.4	35.1	4.8	18.7	38.2	21.4
Advanced degree	7.4	34.5	3.5	19.8	34.7	21.3
Institution type						
Public less than 2 year	10.4	37.8	3.6	20.4	39.7	19.0
Public 2 to 3 year	8.2	33.8	4.6	21.5	37.6	21.1
Public 4 year non-doctoral granting	5.6	33.5	3.9	18.5	37.5	22.5
Public 4 year doctoral granting	4.7	39.8	3.9	18.0	30.2	22.9
Private less than 2 year	5.3	21.0	0.5	6.7	58.4	35.8
Private 2 to 3 year	6.4	40.0	7.5	24.6	16.8	24.1
Private 4 year non doctoral granting	5.2	34.8	5.0	22.6	36.4	21.0
Private 4 year doctoral granting	3.7	36.6	5.6	21.2	26.8	22.3
Proprietary less than 2 year	6.7	33.2	5.3	17.1	39.0	33.5
Proprietary 2 year and above	7.2	27.1	4.5	14.8	42.5	35.4
Institution level						
Less than 2 year	7.3	33.9	4.6	17.6	40.0	29.7
2 to 3 year	8.1	33.6	4.7	21.2	37.5	21.5
4 year non doctoral granting	5.6	33.8	4.3	19.9	37.0	22.9
4 year doctoral granting	4.5	39.3	4.2	18.5	29.6	22.8
Institution control						
Public	6.9	34.9	4.3	20.4	36.5	21.5
Private, not-for-profit	4.8	35.4	5.3	22.0	32.7	22.1
Proprietary	6.9	31.0	5.0	16.3	40.3	34.1

*These groups may be underestimated since the survey was conducted by telephone interview.
– Too few sample cases for a reliable estimate.

Table source: National Center for Education Statistics (1993), Table III.9.
Data source: National Postsecondary Student Aid Study, 1989-90

SCHOOL TO WORK TRANSITION

Table 45. Basis of Exit for Students by Disability: School Year 1990-91

HIGHLIGHTS

- OSEP state-reported data indicate that 45.7% of students with disabilities exiting the educational system did so through receipt of a diploma identical to that for which nondisabled students are eligible. An additional 13.3% graduated with a certificate of completion, certificate of attendance, modified diploma, or through completion of an individualized education program (IEP).

- The percentage of students exiting through each basis varies considerably depending on the student's disability. The students with disabilities who were most likely to graduate with a diploma were students with sensory impairments such as visual impairments (60.3%), hearing impairments (56.8%), and deaf-blindness (52.8%). However, the percentage of students with deaf-blindness should be interpreted with caution given the small number (142) of students with that disability. In addition, more than half of the exiting students with orthopedic impairments (55.3%) and with learning disabilities (51.7%) graduated with a diploma.

- Students with serious emotional disturbance were least likely to receive a diploma (30.8%). For most disability groups, graduation with a diploma was the most common basis of exit. However, for students with serious emotional disturbance, the graduation percentage was low compared to the other bases of exit.

- States reported that 23% of exiters with disabilities dropped out of school in 1990-91. Students with orthopedic impairments (10.1%), visual impairments (12.1%) and hearing impairments (12.2%) are least likely to drop out. The most likely to drop out are students with serious emotional disturbance (36.2%), specific learning disabilities (22.2%), and mental retardation (21.6%).

EXPLANATORY NOTES

This table provides national statistics concerning children who received special educational and related services under IDEA and Chapter 1 of the Elementary and Secondary Education Act (ESEA). These data are reported annually by the states to the Office of Special Education Programs (OSEP) in the U.S. Department of Education.

In accordance with Section 618 of IDEA, each year since 1984-85 OSEP has collected data from states on the number of students with disabilities age 14 and older exiting the educational system. These data are collected by disability, age, and basis of exit: graduated with diploma, graduated with a certificate, reached the maximum age for services, dropped out, and exited with status unknown.

Almost 16% of students with disabilities exiting the educational system left with their status unknown. According to OSEP, this figure varies a great deal from state to state, with a few states accounting for the vast majority of status unknown exiters. Studies of state special education exit data suggest that students who returned to regular education may erroneously be included in the count of status unknown exiters, inflating this figure. This hypothesis is supported by the distribution of status unknown exiters across disabilities. Students with speech or language impairments who are frequently declassified and returned to regular education, are most likely to exit with their status unknown (30.3%).

Table 45. Basis of Exit for Students by Disability: School Year 1990-91

Disability	Diploma		Certificate		Maximum Age		Drop Out		Status Unknown		Total	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Specific learning disabilities	63,590	51.7	13,291	10.8	845	0.7	27,276	22.2	18,059	14.7	123,061	100
Speech or language impairments	5,258	41.3	1,163	9.1	289	2.3	2,174	17.1	3,857	30.3	12,741	100
Mental retardation	15,883	38.7	10,076	24.6	2,127	5.2	8,876	21.6	4,052	9.9	41,014	100
Serious emotional disturbance	9,598	30.8	2,450	7.9	401	1.3	11,613	37.2	7,144	22.9	31,206	100
Hearing impairments	1,841	56.8	530	16.4	48	1.5	395	12.2	428	13.2	3,242	100
Multiple disabilities	1,506	38.7	1,018	26.2	461	11.9	489	12.6	415	10.7	3,889	100
Orthopedic impairments	1,510	55.3	354	13.0	74	2.7	275	10.1	516	18.9	2,729	100
Visual impairments	862	60.3	208	14.6	32	2.2	173	12.1	155	10.8	1,430	100
Other health impairments	1,836	48.6	618	16.4	81	2.2	658	17.4	582	15.4	3,775	100
Deaf-blindness	75	52.8	25	17.6	10	7.0	20	14.1	12	8.5	142	100
All disabilities	101,959	45.7	29,733	13.3	4,368	2.0	51,949	23.3	35,220	15.8	223,229	100

Table source: Office of Special Education Programs (1993), Table 1.9

Table 46. Secondary School Completion of Youth with Disabilities by Disability Category: 1985-86

HIGHLIGHTS

- Of the special education students who were out of school at the time of data collection in 1987, 56.1% had graduated, 32.5% dropped out, 7.5% reached school age limit, and 3.9% had been suspended or expelled.

- Of those who graduated, 75.1% received a regular diploma rather than a special diploma for attendance.

- Dropout rate was highest among emotionally disturbed students (49.5%) and lowest for deaf students (9.4%). Not doing well in school (28.1%), not liking school (30.4%), and other reasons (32.8%) accounted for 96.7% of students who dropped out.

EXPLANATORY NOTES

The data presented here were collected in 1987 for a sample of more than 8,000 youth who represent the national population of secondary special education students who were ages 13 to 21 in the 1985-86 school year. The data were collected in the first phase of the National Longitudinal Transition Study of Special Education Students (NLTS). Additional data were collected in 1990.

Percentages and means are weighted to represent the national population of youth with disabilities and youth in each disability category. Reported percentages are based on those for whom the question was appropriate and who answered the question. The approximate standard errors increase as the sample size decreases, so percentages based on small samples should be interpreted with caution.

There were 3,053 youths who were considered out of school and for whom school completion status was known. An exiter's completion status was derived from two sources: The parent interview and/or the school record abstract. The parent interview source involved asking the following item of parents who said their youth was no longer in secondary school:

> Did (NAME) graduate, voluntarily leave school, was (he or she) suspended or expelled or is (he or she) older than the school age limit?

The school record abstract item asked:

> What was this student's status at the end of the school year?

For 30% of cases, school completion status was based on the parent interview alone. For 16% of cases, responses were based on the school record abstract alone. For the 55% of cases in which both the parent interview and the school record abstract were available, there was agreement between the two sources on the youth's completion status for 78% of cases. For the remaining 22% (351) of cases, discrepancies were noted and resolved on the basis of whether the school or the parent was considered the best source of information.

Table 46. Secondary School Completion of Youth with Disabilities by Disability Category: 1985-1986

School Completion	Total	Primary Disability Category										
		Learning Disabled	Emotionally Disturbed	Speech Impaired	Mentally Retarded	Visually Impaired	Hard of Hearing	Deaf	Orthoped-ically Impaired	Other Health Impaired	Multiply Disabled	Deaf/ Blind
Percent of out-of-school youth who:												
Graduated	56.1	60.9	41.7	62.7	49.8	69.5	72.3	71.6	75.1	65.4	32.2	43.1
Dropped out	32.5	32.2	49.5	28.3	29.9	15.2	14.5	9.4	14.4	25.2	14.5	7.8
Were suspended, expelled	3.9	3.9	5.3	4.2	3.7	1.6	1.0	2.4	2.6	0.7	3.1	0.0
Reached age limit	7.5	3.0	3.5	4.8	16.6	13.7	12.2	16.6	7.9	8.7	50.2	49.2
Number of respondents	3048	534	335	222	459	279	249	355	246	142	182	45
Percent of graduates receiving regular diploma	75.1	87.9	87.1	91.5	46.9	81.1	86.3	70.3	73.3	88.3	32.9	1.2
Number of respondents	1456	245	110	98	219	159	131	213	118	53	82	28
Percent of dropouts whose parents reported they left school because:												
Not doing well in school	28.1	32.7	19.1	30.0	26.3	--	12.7	11.3	15.7	8.9	0.0	--
Didn't like school/bored	30.4	31.2	32.3	41.7	24.9	--	25.6	38.6	21.5	19.6	17.9	--
Had behavior problems	16.6	14.4	26.8	12.1	13.6	--	3.3	2.6	0.0	4.9	4.4	--
Needed/found job	9.4	10.9	5.0	0.0	12.1	--	7.0	0.0	0.0	0.0	0.0	--
Got married/had child	7.8	8.9	5.8	0.0	6.7	--	34.2	15.4	0.0	2.0	0.0	--
Didn't get into program wanted	3.3	5.1	1.2	0.0	0.0	--	3.8	2.6	0.0	0.0	10.3	--
Illness or disability	5.2	2.8	6.9	4.2	7.7	--	13.3	3.5	32.7	49.1	39.6	--
Moved	1.2	0.0	0.7	10.0	5.5	--	1.5	2.6	4.2	0.0	0.0	--
Friends were dropping out	0.4	0.4	0.0	10.5	0.0	--	3.3	5.1	0.0	0.0	0.0	--
Other	32.8	38.5	28.0	30.1	19.3	--	25.8	40.9	34.3	18.5	50.3	--
Number of respondents	363	88	92	19	44	14	24	20	21	16	23	2

Note: Statistics based on subgroups of fewer than 15 respondents are omitted.

Table source: Valdes, Williamson, & Wagner (1990), Table 37A.
Data source: National Longitudinal Transition Study of Special Education Students

Table 47. Services Reported Needed by Youth with Disabilities Out of Secondary School 3 to 5 Years: 1990

HIGHLIGHTS

- Among the most independent youth, one-fourth of unserved youth were perceived by parents to be in need of vocational assistance such as further training, job counseling, or job placement. One in five unserved youth with the most independent profile still were reported by parents to need occupational therapy or life skills training. This finding suggests that there are unmet needs for support services even among youth who have achieved the fullest degree of independence.

- Levels of unmet need were generally higher for youth with less independent profiles. Reported levels of need were lowest in all cases for youth with profile 1 and were highest for all of the services for youth with profiles 5 or 6, although differences were not statistically significant.

EXPLANATORY NOTES

The data in this table are from the National Longitudinal Transition Study of Special Education Students (NLTS) which was designed to report on the experiences of youth with disabilities in the areas of education, employment, and personal independence. The survey included more than 8,000 youth nationwide who were students in special education in secondary school in the 1985-86 school year. Data were collected in 1987, 1989, and 1990. This table includes youth who were already out of secondary school in 1987 and compares their postschool experiences when they had been out of school less than 2 years with their status 3 years later. Parents of youth with disabilities who were not currently receiving services at the time youth had been out of school three to five years were asked if they believed youth needed those services.

Life profiles were developed by Wagner (1992) as a general measure of independence. They are *a priori* clusters of experiences and are not the result of factor analysis, principal component analysis, or other statistical techniques that find empirical data-based relationships among multiple measures. Life profiles reflect the degree of independence of youth in three domains: (a) engagement in work or education related activities outside the home; (b) residential arrangements; and (c) social activities. The six profiles are defined as follows:

Profile 1	Youth were fully independent in all three domains. Profile 1 incorporated 20% of youth with disabilities who had been out of secondary school 3 to 5 years.
Profile 2	Youth were fully independent in two domains. This profile included 43% of youth with disabilities who have been out of secondary school 3 to 5 years.
Profile 3	Youth were at least partially independent in the engagement domain or were living independently, but were not independent in more than one domain. One in 12 youths with disabilities (8%) who had been out of secondary school 3 to 5 years had this profile.
Profile 4	Youth were active in the engagement or residential domain, but not independent in either of them. Fewer than 1 in 10 (9%) of youth had this profile 3 to 5 years after secondary school.
Profile 5	Youth were not active in either the engagement or residential domain, but were not living in an institution. Three to five years after leaving secondary school, 17% of youth had this profile.
Profile 6	Youth were living in institutions. This profile fit 3% of youth 3 to 5 years after secondary school.

Table 47. Services Reported Needed by Youth with Disabilities Out of Secondary School 3 to 5 Years: 1990

Services Reported Needed by Youth	3 to 5 Years After Secondary School, Youth had Profile:											
	Profile 1: Independent 3 Domains		Profile 2: Independent 2 domains		Profile 3: Independent 1 Domain		Profile 4: Active, Not Independent		Profile 5: Not Active		Profile 6: Institutionalized	
Percent and number of youth not receiving needed services, as reported by parent:	n	%	n	%	n	%	n	%	n	%	n	%
Vocational assistance	271	25.5	519	43.3	110	56.1	129	43.0	274	61.2	35	79.5
Occupational therapy/life skills training	328	19.9	584	28.3	118	38.4	151	42.1	280	51.9	24	--
Tutor/reader/interpreter	277	10.8	562	24.8	123	24.9	201	33.3	273	35.8	31	45.0
Speech/language therapy	331	5.4	625	12.4	129	11.4	211	27.5	285	18.3	31	34.0
Personal counseling/therapy	317	15.6	592	21.4	123	20.5	190	28.3	276	40.4	27	--
Physical therapy/mobility training[1]	69	4.2	381	17.7	90	8.3	187	16.4	212	27.6	16	--

[1] Questions regarding physical therapy/mobility training were not asked of respondents regarding youth whose only known disabilities were learning, emotional, hearing, or speech impairments. Therefore, the sample sizes for this question are smaller than for other services.

Note: Percentages are provided only for groups of at least 30 youth.

Table source: Wagner (1992), Table 7-9.

Data source: National Longitudinal Transition Study of Special Education Students

Table 48. Residential Independence of Youth with Disabilities by Disability Categories: 1987

HIGHLIGHTS

- Overall, 88.4% of special education students who were ages 13 to 21 in the 1985-86 school year lived with parents. The smallest percentage of students who lived with parents were deaf/blind students (68.6%), with another 14.3% living in a residential school and 8.6% living in a group home.

- Only .5% of parents had made alterations to their homes to accommodate their child's disability. Of this percentage, 7.5% were orthopedically impaired, 6.2% were multiply disabled, and 3.8% were other health impaired. It should be noted that the item related to whether alterations had been made to the youth's home to accommodate a disability was asked only of parents of youth who were reported as deaf/blind, visually impaired, orthopedically impaired, other health impaired, or multiply handicapped, as a primary or secondary disability by the school or parent. Parents of youth with other disabilities were not asked the item in an effort to reduce the burden of the interview and because such alterations were considered inappropriate to those disabilities. Youth with other disabilities were coded as not having had the alterations. To the extent that youth with other disabilities actually had the alterations, the data underestimate the frequency of home alterations.

EXPLANATORY NOTES

The data presented here were collected in 1987 for a sample of more than 8,000 youth who represent the national population of secondary special education students who were ages 13 to 21 in the 1985-86 school year. The data were collected in the first phase of the National Longitudinal Transition Study of Special Education Students (NLTS). Additional data were collected in 1990.

Percentages and means are weighted to represent the national population of youth with disabilities and youth in each disability category.

Table 48. Residential Independence of Youth with Disabilities by Disability Categories: 1987

Residential Independence Characteristics	Total	Disability Category										
		Learning Disabled	Emotionally Disturbed	Speech Impaired	Mentally Retarded	Visually Impaired	Hard of Hearing	Deaf	Orthoped-ically Impaired	Other Health Impaired	Multiply Disabled	Deaf/ Blind
Percent living:												
With parent	88.4	89.8	83.4	90.8	87.5	86.9	89.9	83.7	91.2	90.4	76.7	68.8
Alone	0.9	1.0	1.4	0.9	0.4	1.9	1.4	1.8	0.8	1.1	0.2	1.3
With spouse/roommate	3.1	3.9	3.2	2.6	1.6	2.6	2.5	3.8	1.6	1.7	1.2	0.0
With other family member	3.4	3.3	4.2	2.6	3.8	2.0	2.9	2.5	2.7	2.7	1.9	1.0
In residential/boarding school	0.9	0.5	1.4	0.5	1.3	3.6	0.7	6.1	0.4	1.4	4.1	14.3
In college dormitory	0.1	0.1	0.0	0.4	0.1	1.6	1.2	0.9	0.5	0.0	0.0	0.0
In group home	1.0	0.0	1.7	1.5	2.8	0.9	0.9	0.2	1.3	2.2	6.1	8.6
In mental health facility for disabled	1.0	0.4	2.3	0.2	1.8	0.6	0.2	0.4	1.4	0.3	8.2	6.0
In correctional facility	0.5	0.4	1.4	0.3	0.6	0.0	0.2	0.0	0.0	0.0	0.1	0.0
Other	0.5	0.7	1.0	0.2	0.1	0.1	0.1	0.5	0.2	0.3	1.3	0.0
Number of respondents	7185	987	643	497	950	754	693	817	672	440	643	89
Percent of institutionalized youth who have been in institutions:												
Less than 6 months	33.5	--	40.7	--	19.5	20.4	--	--	30.2	4.4	12.1	--
6 to 12 months	22.3	--	27.0	--	18.6	40.0	--	--	16.7	38.1	11.3	--
13 to 36 months	20.2	--	27.2	--	28.2	25.0	--	--	19.1	18.6	8.7	--
More than 36 months	24.0	--	5.1	--	33.7	14.5	--	--	34.1	39.0	68.0	--
Number of respondents	275	9	32	9	52	15	6	7	21	16	95	13
Percent making alterations to home to accommodate disability	0.5	0.1	0.1	0.0	0.8	0.6	0.0	0.0	7.5	3.8	6.2	0.0
Number of respondents	6749	967	624	482	842	735	636	763	640	410	571	79

Note: Statistics based on subgroups of fewer than 15 respondents are omitted.
Table source: Valdes, Williamson, & Wagner (1990), Table 38A.
Data source: National Longitudinal Transition Study of Special Education Students

Table 49. Types of Services Received from Vocational Rehabilitation, by Severity of Youth's Disability: 1990

HIGHLIGHTS

- Overall, 39.7% of transitional youth clients received support for postsecondary education or training from vocational rehabilitation (VR). This support ranged from tuition, fees, and expenses for attending college to attendance in technical institutes. Youth whose disabilities were not severe (55.2%) more often enrolled in postsecondary institutions than those with severe disabilities (33.3%).

- Most frequently, VR paid for skill or vocational training. Overall, 23.7% of all youth with disabilities received this type of assistance, with youth whose disabilities were not severe more often receiving this service (32.3% versus 20.1%).

- Those without severe disabilities were more than twice as often supported to attend community college, while youth with severe and nonsevere disabilities were about as likely to receive support to attend four-year colleges. Wine et al. (1993) explain this finding by noting that youth with hearing impairments were both most likely to receive support for postsecondary education and were most likely to go to four-year institutions.

- Sixty percent of transitional youth clients received vocational services during their VR experience. Youth with severe disabilities were twice as likely to receive such services (70.2% versus 35.8%). They also most often received work adjustment training (35.5%) followed by sheltered work (26.7%), and supported employment (19.4%). Youth whose disabilities were not severe most often received work adjustment (31.2%).

- About two-thirds of youth with disabilities received some type of supportive services to assist them in pursuing their rehabilitation program. Most often, this support was in the form of transportation, received by 37.7% of youth with severe disabilities and 32.1% of those whose disabilities were not severe. Other types of supportive services were maintenance payments received by 18.6% of youth with severe disabilities and 25.9% of those with nonsevere disabilities.

EXPLANATORY NOTES

The analyses of the VR experiences reported in this table combine data from the National Longitudinal Transition Study of Special Education Students with data collected from the VR case files of two groups of NLTS youth: those who applied for VR services and those who were accepted for VR services.

The purpose of the analyses was to use information on these youths' VR participation collected from their VR case files in conjunction with other variables from the NLTS database. The primary student sample for the VR study was chosen from a random sample of 13 states. In all, parent reports identified a total of 300 students in 13 states who had applied for VR services. After verifying these reports with state VR records, 25% were found never to have applied for VR services and were dropped from the sample. In addition to the VR sample, a second sample of NLTS youth who neither applied for nor received VR services was selected as a comparison group for analysis of the relationship of VR services to student outcomes. Many of the percentages are based on relatively small sample sizes, so differences in percentages only suggest general trends in the data.

Table 49. Types of Services Received from Vocational Rehabilitation, by Severity of Youth's Disability: 1990

Type of Service	Percent of Youth with Severe Disabilities	Percent of Youth with Nonsevere Disabilities	Total
Postsecondary education	33.3†	55.2	39.7
College tuition and fees	5.7	5.4	5.6
Community college tuition and fees	8.4	17.7	11.1
Skill or vocational training	20.1	32.3	23.7
Vocational services and placement	70.2†	35.8	60.2
Work adjustment training	35.5	31.2	34.2
Sheltered work	26.7	14.9	23.2
Supported employment	19.4	6.1	15.5
On-the-job training	13.3	1.7	10.0
Supportive services	69.2†	58.6	66.1
Transportation assistance	37.7	32.1	36.1
Maintenance payments	18.6	25.9	20.7
Physical restoration	15.2	17.4	15.8
Mental restoration	5.6	0.8	4.2
Residential placement	12.7	0.0	9.0
Postemployment services	8.5	0.6	6.2
Extended evaluation	10.6	0.3	7.6

†Youth could receive multiple services.

Table source: Wine, Hayward, & Wagner (1993), Table 17.

Data source: National Longitudinal Transition Study of Special Education Students

Table 50. Types of Services Received from VR, by Youth's Primary Disability: 1990

HIGHLIGHTS

- Support for postsecondary enrollment varied substantially according to type of disability. Youth with hearing (77.5%) or visual impairments (71.7%) were most likely to receive support for postsecondary education or training, followed by those with learning disabilities (64.9%).
- Youth with learning disabilities typically enrolled in vocational programs (40.2%), while youth with visual impairments most often went to community college (66.3%). Those with hearing impairments most often enrolled in four-year colleges (35.8%) and community colleges (26.7%).
- About one-third of youth with orthopedic impairments or mental illness received postsecondary education or training services, while very few (16.6%) of youth with mental retardation enrolled. All of the latter entered skill or vocational training programs rather than college.
- Receipt of vocational services varied greatly according to disability classification. Nearly all youth clients with mental retardation (89%) received such services, generally participating in either work adjustment (52.5%) or sheltered work (53.6%). Substantially fewer (20.7%) received supported employment services. A majority of youth clients with orthopedic impairments received vocational services (57%), nearly all in work adjustment training. A substantial percentage (44.1%) of those with learning disabilities also received services, generally either work adjustment training (26.8%) or on-the-job training (17.3%).
- Specific types of supportive services provided by VR varied. Youth with mental retardation who received support were provided transportation assistance (58.4%), while almost all of the clients with visual impairments received physical restoration (87.2%). Youth with hearing impairments received physical restoration services (39.9%) or transportation assistance (34.3%). Youth with orthopedic disabilities often received transportation (48.4%), and clients with mental illness, least likely to receive supportive services (40.6% overall), tended to receive transportation assistance (31.5%) or maintenance payments (31.5%). Youth with learning disabilities most often received maintenance.

EXPLANATORY NOTES

The analyses of the VR experiences reported in this table combine data from the National Longitudinal Transition Study of Special Education Students with data collected from the VR case files of two groups of NLTS youth: those who applied for VR services and those who were accepted for VR services.

The purpose of the analyses was to use information on these youths' VR participation collected from their VR case files in conjunction with other variables from the NLTS database. The primary student sample for the VR study was chosen from a random sample of 13 states. In all, parent reports identified a total of 300 students in 13 states who had applied for VR services. After verifying these reports with state VR records, 25% were found never to have applied for VR services and were dropped from the sample. In addition to the VR sample, a second sample of NLTS youth who neither applied for nor received VR services was selected as a comparison group for analysis of the relationship of VR services to student outcomes. Many of the percentages are based on relatively small sample sizes, so differences in percentages only suggest general trends in the data.

Table 50. Types of Services Received from VR, by Youth's Primary Disability: 1990

Type of Service	Visual Impairment	Hearing Impairment	Orthopedic Impairment	Mental Illness	Mental Retardation	Learning Disability	Other
Postsecondary education	71.7	77.5	33.6	35.1	16.6	64.9	32.9
College tuition	6.8	35.8	13.1	0.0	0.0	5.3	1.2
Community college tuition	66.3	26.7	9.5	3.5	0.0	19.3	1.9
Skill or vocational training	0.0	20.3	12.6	31.5	16.6	40.2	31.0
Vocational services/placement	7.9	22.9	57.0	55.9	89.0	44.1	40.1
Work adjustment training	7.9	18.7	53.8	0.0	52.5	26.8	7.0
Sheltered work	4.6	4.9	6.5	0.0	53.6	0.0	2.1
Supported employment	0.0	0.0	5.2	55.9	20.7	0.0	38.0
On-the-job training	0.0	6.3	3.4	0.0	10.7	17.3	7.0
Supportive services	87.2	66.8	60.1	40.6	76.6	62.5	37.4
Transportation assistance	14.8	34.3	48.4	31.5	58.4	13.1	2.1
Maintenance payments	0.0	14.3	1.7	31.5	10.0	43.7	32.6
Physical restoration	87.2	39.9	17.7	9.1	5.1	17.9	1.2
Mental restoration	14.6	4.2	3.5	0.0	7.0	0.0	0.0
Residential placement	0.0	5.1	33.9	0.0	14.8	0.0	2.1
Postemployment services	0.0	17.0	3.6	0.0	0.2	17.3	3.6
Extended evaluation	0.0	2.4	1.2	0.0	11.5	0.0	29.3

Table source: Wine, Hayward, & Wagner (1993), Table 18.

Data source: National Longitudinal Transition Study of Special Education Students

Table 51. Employment Outcomes of Successfully Rehabilitated Youth, by Type of Placement, Severity of Disability, and Type of Disability: 1990

HIGHLIGHTS

- This table reports the employment situations obtained by 26 transitional youth who were closed from VR as successful rehabilitants prior to the time of data collection in Fall 1991. A substantial majority (74.4%) of youth clients who were closed as successfully rehabilitated from VR achieved either full-time or part-time competitive employment, while 17.7% entered sheltered work settings. Only 4.7% entered supported employment.

- Overall, 68.6% of 26 closures were youth with a severe disability which is consistent with their distribution in the population of youth clients. The employment situations of youth clients with severe disabilities differed substantially from those of youth whose disabilities were not severe. Half of the latter obtained full-time competitive jobs, as opposed to only 29.2% of youth with severe disabilities. Clients with severe disabilities more often worked part-time (45.6% of 26 closures with severe disabilities).

- Youth with hearing impairments or learning disabilities who were closed as successfully rehabilitated most often entered full time competitive employment (76.6% and 64%, respectively). The same was true for mental illness. However, these youth represent only 6% of youth clients and represent less than 1% of the 26 closures.

- Employment patterns for youth with mental retardation differed from those of youth with hearing impairments or learning disabilities but were somewhat similar to the patterns found for youth with orthopedic impairments. For both groups, the employment outcome was most often a part-time competitive job (47.8% for youth with mental retardation and 32.9% for those with orthopedic impairments), followed by sheltered work (30.3% for both groups).

EXPLANATORY NOTES

The analyses of the VR experiences reported in this table combine data from the National Longitudinal Transition Study of Special Education Students with data collected from the VR case files of two groups of NLTS youth: those who applied for VR services and those who were accepted for VR services.

The purpose of the analyses was to use information on these youths' VR participation collected from their VR case files in conjunction with other variables from the NLTS database. The primary student sample for the VR study was chosen from a random sample of 13 states. In all, parent reports identified a total of 300 students in 13 states who had applied for VR services. After verifying these reports with state VR records, 25% were found never to have applied for VR services and were dropped from the sample. In addition to the VR sample, a second sample of NLTS youth who neither applied for nor received VR services was selected as a comparison group for analysis of the relationship of VR services to student outcomes.

Many of the percentages are based on relatively small sample sizes. Differences in percentages should be interpreted as suggestive of general trends in the data.

Table 51. Employment Outcomes of Successfully Rehabilitated Youth, by Type of Placement, Severity of Disability, and Type of Disability: 1990

Severity and Type of Disability	Type of Placement %					
	Full Time	Part Time	Supported Employment	Sheltered Work	Other	Percent of All Rehabilitated Youth
Overall	35.5	38.9	4.7	17.7	3.1	100.0
Severity of Disability						
Severe	29.2	45.6	4.3	16.1	4.5	68.6
Nonsevere	49.1	24.2	5.7	21.1	0.0	31.4
Disability						
Visual impairment	0.0	0.0	0.0	0.0	100.0	0.8
Hearing impairment	76.6	16.2	0.0	0.0	7.2	3.8
Orthopedic impairment	16.2	42.9	10.5	30.3	0.0	2.0
Mental illness	100.0	0.0	0.0	0.0	0.0	0.3
Mental retardation	10.0	47.9	8.2	30.3	3.6	55.5
Learning disability	64.0	36.0	0.0	0.0	0.0	28.3
Other	89.5	7.3	0.0	3.1	0.0	9.2

Table source: Wine, Hayward, & Wagner (1993), Table 21.

Data source: National Longitudinal Transition Study of Special Education Students

Table 52. Occupations of Employed Men and Women with Disabilities: 1987 and 1990

HIGHLIGHTS

○ About the same percentages of men and women were in each of the major occupational categories in 1987 and 1990, although some shifting within service occupations occurred among women. The percentage of women in food service occupations dropped by 13.1% from 1987 to 1990.

○ Three to five years after they left secondary school, men and women were still distributed very differently among the occupational categories, with women more likely than men to be clerical (22% versus 5%) or service workers (44% versus 20%). Women were also less likely than men to be craft workers (less than 1% versus 17%) or laborers (3% versus 33%).

EXPLANATORY NOTES

The data in this table are from the National Longitudinal Transition Study of Special Education Students which was designed to report on the experiences of youth with disabilities in the areas of education, employment, and personal independence. The survey included more than 8,000 youth nationwide who were students in special education in secondary school in the 1985-86 school year. Data were collected in 1987, 1989, and 1990. This table includes youth who were already out of secondary school in 1987 and compares their postschool experiences when they had been out of school less than 2 years with their status 3 years later. This subsample includes only youth for whom data were collected in both 1987 and 1990 so that trends over time could be tracked.

This table shows aggregate data on occupational mobility. However, aggregate figures can mask employment changes experienced by individual youth. For example, if the same number of youth moved into an occupational category as moved out of it, no change in the aggregate percentage of youth with that kind of job would be noted, but substantial fluctuation in jobs would have occurred. Wagner et al. (1992) also analyzed job movement among youth employed in both 1987 and 1990. Significantly greater movement of individual youth is evident than aggregate figures revealed. Overall, fewer than half of youth working at both time points were working in the same job category 3 to 5 years after secondary school as they were when out of school less than 2 years.

Table 52. Occupations of Employed Men and Women with Disabilities: 1987 and 1990

	Men			Women		
Occupation	Out of School Less Than 2 years %	Out of School 3 - 5 Years %	Difference %	Out of School Less than 2 Years %	Out of School 3 - 5 Years %	Difference %
Professional, managerial, sales	4.6	5.9	1.3	4.6	9.6	5.0
Clerical workers	13.1	5.3	–7.8	21.5	22.4	.9
Craft workers	13.2	16.9	3.7	0.9	0.3	–.6
Operatives	15.2	19.5	4.3	17.1	20.8	3.7
Laborers	27.2	32.8	5.6	7.7	3.0	–4.7
Service workers						
Janitors and maids	5.7	3.9	–1.8	3.9	6.5	2.6
Food service	12.9	9.5	–3.4	27.8	14.7	–13.1
Child care, babysitting	0.2	0.1	–.1	9.0	2.5	–6.5
Other	7.8	6.1	–1.7	7.5	20.2	12.7
Number	600	579		249	225	

Table source: D'Amico & Blackorby (1992), Table 4-7.

Data source: National Longitudinal Transition Study of Special Education Students

Table 53. Patterns of Employment Over Time of Out-of-School Youth, By Disability Category: 1987 and 1990

HIGHLIGHTS

- One-third of youth with disabilities were employed at both 1987 and 1990, a rate that ranged from 47% of youth with learning disabilities to 8.5% of those with multiple disabilities. Youth with learning disabilities were significantly more likely to have been employed at both times than were youth in nearly every other disability category.

- Overall, about as many youth had a different employment status at the two time points as were consistently employed. But, as might be expected given the overall upward trend in employment rates, more youth found jobs (22.9%) than lost them (13.3%). Patterns varied greatly between disability categories. Among those with mental retardation or learning disabilities, for example, almost twice as many youth became employed (23.9%) as lost employment (12.9%). However, for the remaining categories, youth were about equally likely to have experienced change in either direction.

- Stability of nonemployment is very high for youth in some disability categories. Nearly equal proportions of youth were not employed at both points in time as were employed at both points. Although 30.4% of youth overall were not employed at either time period, this rate ranged from 17.5% of those with learning disabilities to almost three-fourths of youth who had orthopedic or multiple impairments or who were deaf/blind.

EXPLANATORY NOTES

The data in this table are from the National Longitudinal Transition Study of Special Education Students which was designed to report on the experiences of youth with disabilities in the areas of education, employment, and personal independence. The survey included more than 8,000 youth nationwide who were students in special education in secondary school in the 1985-86 school year. Data were collected in 1987, 1989, and 1990. This table includes youth who were already out of secondary school in 1987 and compares their postschool experiences when they had been out of school less than 2 years with their status 3 years later. This subsample includes only youth for whom data were collected in both 1987 and 1990 so that trends over time could be tracked.

Table 53. Patterns of Employment Over Time of Out-of-School Youth, By Disability Category: 1987 and 1990

Disability Category	Percentage of youth: Not Employed at Either Time	Lost Employment	Became Employed	Employed at Both Times	n
All conditions	30.4	13.3	22.9	33.4	1,781
Learning disabled	17.5	12.4	22.9	47.2	312
Emotionally disturbed	32.5	19.0	24.9	23.7	185
Speech impaired	21.2	15.2	27.4	36.2	123
Mentally retarded	50.3	12.9	23.9	12.9	251
Visually impaired	61.5	8.8	15.3	14.4	169
Hard of hearing	39.8	18.5	10.6	31.1	140
Deaf	41.4	14.2	21.6	22.8	243
Orthopedically impaired	73.3	5.6	7.4	13.6	153
Other health impaired	47.2	13.9	19.7	19.3	80
Multiply handicapped	73.0	10.2	8.3	8.5	94
Deaf/blind	72.7	11.2	5.5	10.5	31

Not employed at either time = not employed at interview point in 1987 or 1990.

Lost employment = employed at interview point in 1987 but not in 1990.

Became employed = not employed at interview point in 1987 but employed in 1990.

Employed at both times = employed at interview points in 1987 and 1990.

Table source: D'Amico & Blackorby (1992), Table 4-2.

Data source: National Longitudinal Transition Study of Special Education Students

FEDERAL BENEFITS PROGRAMS

Table 54. Number and Percent Distribution of Blind and Disabled Children Receiving Federally Administered Supplemental Security Income (SSI) Payments and Not Transferred from Prior State Programs, by Diagnostic Group, Age and Sex: December 1992.

HIGHLIGHTS

- An estimated 726,400 children were due to receive Supplemental Security Income payments on January 1, 1993. Of this number, diagnoses were available for 645,800 recipients. Of the children for whom diagnoses were available, 41.4% of recipients had mental retardation. The next largest diagnostic group was for nervous system and sense organ disease (16.4%) and mental disorders (15.9%). This pattern was consistent across sex and age groups.

EXPLANATORY NOTES

The Supplemental Security Income (SSI) program provides income support to persons aged 65 and older, blind or disabled adults, and blind or disabled children. Eligibility requirements and federal payment standards are nationally uniform. The program is administered by the Social Security Administration.

To be eligible for SSI payments as a child, an individual must be under age 18 (or under age 22 if he or she is a full-time student), unmarried, and must meet applicable disability, income and resource criteria.

Table 54. Number and Percent Distribution of Blind and Disabled Children Receiving Federally Administered Supplemental Security Income (SSI) Payments and Not Transferred from Prior State Programs, by Diagnostic Group, Age and Sex: December 1992.

Diagnostic Group	Total	Total			Male			Female		
		Under 10	10 - 17	18 - 21	Under 10	10 - 17	18 - 21	Under 10	10 - 17	18 - 21
Total	726,400	268,000	320,400	138,000	167,100	194,600	78,000	100,900	125,800	60,000
Diagnosis available, number	645,800	243,800	289,100	112,900	152,300	176,700	63,700	91,500	112,400	49,200
Diagnosis available, percent	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Infectious and parasitic diseases	0.3	0.5	0.2	0.7	0.7	0.3	0.5	0.2	--	1.0
Neoplasms	1.9	2.2	1.8	1.2	1.5	2.0	1.9	3.3	1.4	0.2
Endocrine, nutritional, metabolic diseases	1.2	1.4	1.1	1.2	1.4	0.9	0.5	1.4	1.4	2.0
Diseases of blood and blood-forming organs	1.7	2.1	1.5	1.1	2.1	1.4	1.1	2.0	1.7	1.0
Mental disorders (other than mental retardation)	15.9	13.2	18.9	16.6	16.3	23.4	16.6	8.0	11.7	16.5
Mental retardation	41.4	32.0	47.9	49.7	32.9	46.0	52.1	30.4	50.8	46.5
Diseases of:										
Nervous system and sense organs	16.4	18.0	14.3	18.7	16.3	12.3	17.6	21.0	17.4	20.1
Circulatory system	0.8	1.1	0.6	0.7	1.2	0.5	0.6	0.9	0.8	0.8
Respiratory system	2.2	3.2	1.5	1.0	3.3	1.8	0.8	3.1	1.0	1.2
Digestive system	0.3	0.7	0.1	0.1	0.5	0.1	--	1.0	0.2	0.2
Genitourinary system	0.5	0.2	0.8	1.0	0.3	0.6	0.2	0.2	1.1	2.0
Skin and subcutaneous tissue	0.1	0.2	--	0.1	0.2	--	0.2	0.2	0.1	--
Musculoskeletal system	1.5	1.8	1.2	1.7	1.2	1.1	1.1	2.8	1.4	2.4
Congenital anomalies	6.3	8.2	5.0	2.6	7.5	4.2	2.5	9.5	6.2	2.6
Injuries	0.9	0.8	0.8	2.9	1.1	1.0	3.6	0.4	0.4	2.0
Other	8.5	14.4	4.4	1.0	13.7	4.4	0.8	15.6	4.4	1.2

Table Source: Social Security Administration (1993), Tables 7.F2 and 7.F1.

Table 55. Number and Percent of Children Receiving Supplemental Security Income (SSI) Payments by Selected Characteristics: December 1991

HIGHLIGHTS

- In December 1991, 61.6% of children receiving SSI payments were age 12 or under; 21.2% were under age 6.
- Boys were more likely than girls to be SSI recipients, by about 3 to 2.
- Among child SSI recipients, 73.9% lived with their parent(s). Three percent of the entire group were patients in a medical facility where more than half of the cost of their care was covered by the Medicaid program.
- Less than 2% of SSI children had earnings in December 1991, not surprising in view of the age of this population. Almost half of the group (44.9%) had some type of unearned income, but few of these children were receiving benefits from Social Security (7.8%). What the child recipients typically received was assistance based on need, child support, and/or income deemed from the parents with whom they live.
- More than half (56%) of SSI children were disabled based on a mental disorder; 43.8% were mentally retarded. The only other diagnostic category with a sizable percentage (18.6%) of child recipients was diseases of the nervous system and sense organs, which included all of the approximately 8,000 blind children who received SSI payments.

EXPLANATORY NOTES

The Supplemental Security Income (SSI) program provides income support to persons aged 65 and older, blind or disabled adults, and blind or disabled children. Eligibility requirements and federal payment standards are nationally uniform. The program is administered by the Social Security Administration.

To be eligible for SSI payments as a child, an individual must be under age 18 (or under age 22 if he or she is a full-time student), unmarried, and must meet applicable disability, income and resource criteria.

This table is based on the Supplemental Security Record (SSR), the main administrative database for the SSI program. The table is based on the basic SSI 10% sample file for December 1991, and represents the number of persons due to receive an SSI payment on January 1, 1992.

Table 55. Number and Percent of Children Receiving Supplemental Security Income (SSI) Payments by Selected Characteristics: December 1991

Characteristic	Children Receiving SSI	
	Number	Percent
Total	431,730	100.0
Age		
Under 6	91,590	21.2
6 - 12	174,470	40.4
13 - 17	118,930	27.5
18 - 21	46,740	10.8
Sex		
Female	170,960	39.6
Male	260,770	60.4
Living Arrangement		
Own household	76,950	17.8
Another's household	23,620	5.5
Parent's household	318,850	73.9
Medicaid institution	12,310	2.9
Income		
Earnings	7,370	1.7
Unearned income	193,650	44.9
Social Security	33,480	7.8
Veterans	1,600	.4
Other	158,570	36.7
Diagnosis available	336,910	100.0
Infectious and parasitic diseases	1,370	.4
Neoplasms	7,530	2.2
Endocrine, nutrition, and metabolic disorders	13,530	4.0
Mental disorders		
Psychotic and neurotic disorders	41,100	12.2
Mental retardation	147,730	43.8
Diseases of the		
Nervous system and sense organs	62,630	18.6
Circulatory system	2,910	.9
Respiratory system	7,740	2.3
Digestive system	1,250	.4
Musculoskeletal system and connective tissues	5,740	1.7
Congenital anomalies	18,320	5.4
Other	27,150	8.1

Note: Based on a 10% sample file. Number of persons and average payments due January 1, 1992.

Source: Kennedy (1992), Tables 3 and 4.

Table 56. Number and Percent of Children Served by University Affiliated Programs for Persons with Developmental Disabilities: Fiscal Year 1991

HIGHLIGHTS

- Of the 53,675 clinic-based clients served by University Affiliated Programs for Persons with Developmental Disabilities, 44,741 (83%) were children and youth ages 0 to 21.

- Information on age and race were available for 43,551 of the children and youth served. Children ages 2 through 11 comprised 75% of all children and youth served. Fifty-four percent of the children served were white, 22% were black, and 10% were Hispanic.

EXPLANATORY NOTES

These data were collected by the University Affiliated Programs (UAP) for Persons with Developmental Disabilities. The data on UAP clinic-based clients include information about individual clients and families who received direct services from UAPs. UAP clients are those who receive evaluations and direct services in UAP clinics and/or through UAP interdisciplinary teams. UAP is the primary repository of the client's records and is legally responsible for maintaining them.

Table 56. Number and Percent of Children Served by University Affiliated Programs for Persons with Developmental Disabilities: Fiscal Year 1991

Race/Ethnicity	Age										Total
	0 - 1		2 - 5		6 - 11		12 - 17		18 - 21		
White	685	3%	8,717	37%	8,186	35%	4,209	18%	1,505	6%	23,302
Black	636	7%	3,752	40%	3,534	38%	1,160	12%	320	3%	9,402
Hispanic	247	5%	1,963	43%	1,644	36%	508	11%	196	4%	4,558
American Indian/Alaskan Native	5	2%	213	67%	60	19%	33	10%	9	3%	320
Asian American/Pacific Islander	7	2%	123	40%	114	37%	40	13%	23	7%	307
Other	240	4%	2,225	39%	2,357	42%	583	10%	257	5%	5,662
Total	1820	4%	16,993	39%	15,895	36%	6,533	15%	2,310	5%	43,551

Table Source: NIRS (1991), page 20.

Table 57. Vocational Rehabilitation Clients Under 21 Years of Age by Major Disabling Condition and Source of Referral: Fiscal Year 1991

HIGHLIGHTS

- Of the 68,741 vocational rehabilitation (VR) clients whose cases were successfully or unsuccessfully closed by VR, 26.8% had mental retardation, 22.5% had learning disabilities, 14.2% had mental illness, and 11.6% had orthopedic impairments.

- Of the youth whose cases were closed, 52.7% had been referred to VR by their elementary or high schools.

EXPLANATORY NOTES

The State-Federal Program of Vocational Rehabilitation (VR) is authorized by the Rehabilitation Act of 1973, as amended, and administered by the Rehabilitation Services Administration at the federal level. The program provides individualized rehabilitation services to disabled persons to help them attain, maintain, or regain employment.

The RSA-911 system contains personal, economic, program-related and outcome data on each of the 600,000 disabled persons whose cases are closed, whether successfully or not, each year by over 80 state vocational rehabilitation agencies.

Age was determined at time of application, not at time of closure.

Table 57. Vocational Rehabilitation Clients Under 21 Years of Age by Major Disabling Condition and Source of Referral: Fiscal Year 1991

Major Disabling Condition	Number	Percent
Total	68,741	100.0
Visual impairments	2,555	3.7
Hearing Impairments	3,854	5.6
Orthopedic impairments	8,003	11.6
Absence of limbs	402	.6
Mental illness	9,788	14.2
Substance abuse	2,701	3.9
Mental retardation	18,390	26.8
Respiratory disorders	150	.2
Digestive disorders	287	.4
Heart/Circulatory conditions	430	.6
Genitourinary	289	.4
Learning disabilities	15,470	22.5
All other disabilities	6,422	9.3
Not reported	197	.2

Source of Referral	Number	Percent
Total	68,900	100.0
Educational institution		
College or university	836	1.2
Vocational school	1,248	1.8
Elementary or high school	36,313	52.7
School for handicapped	2,629	3.8
Other educational institution	731	1.1
Hospitals or sanatoriums	2,082	3.0
Health organizations	3,222	4.7
Welfare agency	779	1.1
Other public organization	4,973	7.2
Other private organization	969	1.4
Self-referred person	6,720	9.8
Physician	1,349	2.0
Other individual	7,049	10.2

Table source: Unpublished tabulations from the RSA-911 Case Service Reports for Fiscal Year 1991 provided by Larry Mars, Rehabilitation Services Administration.

STATE-LEVEL DATA

Table 58. Prevalence of Chronic Conditions Causing Activity Limitations Among Noninstitutionalized Persons Under 22 Years of Age, by State: 1985-89

HIGHLIGHTS

- This table presents synthetic estimates of the prevalence of activity-limiting chronic conditions for the 50 states and the District of Columbia. Estimates are for state-level prevalence per 100,000 as well as the number of children and youth with chronic conditions causing activity limitations. The overall prevalence of chronic conditions causing activity limitations ranged from 4.9% in Pennsylvania and several other Northeastern states to 5.6% in Wisconsin and several other states in the Midwest.

EXPLANATORY NOTES

The information in this table is based on the National Health Interview Survey. To increase precision of the estimates, five years of survey data, from 1985 to 1989, were combined. The combined NHIS sample included 173,728 children and youth under age 22. The average response rate for all years exceeded 95% and overall prevalence levels were similar for each of the five years.

Synthetic estimation was used to produce states estimates of the prevalence of childhood chronic conditions from national survey data. Synthetic estimation is a technique for obtaining small area estimates when data are available only for large areas. It is a relatively simple procedure and the costs are minimal compared to the costs of conducting a state-level survey. A major disadvantage is the inability to adjust national estimates according to all of the characteristics at the state level that may influence prevalence.

Table 58. Prevalence of Chronic Conditions Causing Activity Limitations Among Noninstitutionalized Persons Under 22 Years of Age, by State: 1985-89

State	State Prevalence per 100,000	Estimated number of cases in state
Alabama	5,330	70,318
Alaska	5,076	9,108
Arizona	5,045	54,763
Arkansas	5,345	45,138
California	5,108	455,168
Colorado	5,110	53,004
Connecticut	4,903	45,139
Delaware	5,297	10,423
District of Columbia	5,306	7,839
Florida	5,338	190,022
Georgia	5,369	106,489
Hawaii	5,060	16,354
Idaho	5,160	18,798
Illinois	5,544	202,802
Indiana	5,553	95,638
Iowa	5,537	50,025
Kansas	5,574	42,889
Kentucky	5,361	60,965
Louisiana	5,337	80,186
Maine	4,879	17,237
Maryland	5,370	76,415
Massachusetts	4,905	85,130
Michigan	5,572	170,147
Minnesota	5,513	83,564
Mississippi	5,349	50,137
Missouri	5,535	95,821
Montana	5,133	13,761
Nebraska	5,510	28,515
Nevada	5,083	16,228
New Hampshire	4,876	15,653
New Jersey	4,930	110,576
New Mexico	5,148	27,835
New York	4,906	261,876
North Carolina	5,350	101,435
North Dakota	5,558	12,868
Ohio	5,602	210,151
Oklahoma	5,310	53,994
Oregon	5,173	46,100
Pennsylvania	4,874	176,200
Rhode Island	4,931	15,871
South Carolina	5,324	56,041
South Dakota	5,571	14,157
Tennessee	5,334	83,875
Texas	5,314	330,205
Utah	5,071	36,424
Vermont	4,972	7,842
Virginia	5,321	97,736
Washington	5,092	77,180
West Virginia	5,361	33,019
Wisconsin	5,621	81,114
Wyoming	5,126	8,301

Table source: Newacheck (1991), Tables 2 - 52.
Data source: National Health Interview Survey, 1985-89

Table 59. Children in State Institutions As a Percentage of All Residents, by Age and State, on June 30, 1991

HIGHLIGHTS

- Nationwide, 8.8% of all state institution residents were 21 years or younger. However in 9 states less than 3% of state institution residents were in the birth to 21 year age range (Alaska, Arizona, Massachusetts, Minnesota, New Hampshire, Pennsylvania, Rhode Island, Vermont, and West Virginia). In 8 states more than 15% of state institution populations were composed of persons 21 years and younger (Arkansas, Kansas, Louisiana, Mississippi, Nevada, New Mexico, Oklahoma, and South Carolina).

EXPLANATORY NOTES

The information about characteristics of state institution residents in fiscal year 1991 is based on a mail survey of 288 individual state institutions for persons with mental retardation and related conditions with 16 or more residents operating in the United States on June 30, 1991. These facilities included traditional state mental retardation/developmental disabilities (MR/DD) institutions and MR/DD units contained within other state-operated institutions. The survey was conducted by the University of Minnesota, Center on Residential Services and Community Living and the National Association of Superintendents of Public Residential Facilities for the Mentally Retarded (NASPRFMR) as part of the National Recurring Data Set Project on Residential Services.

Data in this table are based on the reports of state institutions which housed 66,784 (84.1%) of the 79,407 state institution residents on June 30, 1991.

Table 59. Children in State Institutions As a Percentage of All Residents, by Age and State, on June 30, 1991

State	Age of Resident in Years				
	0 - 4	5 - 9	10 - 14	15 - 21	Total Ages 0 - 21
Alabama	0.0	.1	1.0	6.7	7.8
Alaska	0.0	0.0	0.0	0.0	0.0
Arizona	0.0	0.0	0.0	.5	0.5
Arkansas	0.0	.5	4.0	13.9	18.4
California	.9	1.8	2.1	7.7	12.5
Colorado	0.0	1.2	.9	6.5	8.6
Connecticut	–	–	–	–	–
Delaware	0.0	0.0	1.5	6.6	8.1
District of Columbia	0.0	0.0	0.0	–	0.0
Florida	0.0	0.0	0.0	4.2	4.2
Georgia	.6	1.4	2.0	8.6	12.6
Hawaii	.7	0.0	2.2	11.9	14.8
Idaho	1.7	1.2	2.3	7.6	12.8
Illinois	0.0	.2	.9	5.3	6.4
Indiana	0.0	0.0	.1	4.1	4.2
Iowa	.1	.3	2.2	6.3	8.9
Kansas	.1	3.6	4.7	13.8	22.2
Kentucky	0.0	.1	1.6	9.6	11.3
Louisiana	.2	1.2	4.0	11.7	17.1
Maine	0.0	0.0	0.0	8.3	8.3
Maryland	.1	.4	1.5	4.6	6.6
Massachusetts	0.0	0.0	0.0	.5	0.5
Michigan	0.0	.3	.4	5.2	5.9
Minnesota	0.0	0.0	0.0	2.2	2.2
Mississippi	.1	1.2	3.0	11.5	15.8
Missouri	.4	.5	2.2	8.8	11.9
Montana	.5	0.0	1.1	3.2	4.8
Nebraska	0.0	.6	1.1	3.9	5.6
Nevada	0.0	.6	6.4	18.5	25.5
New Hampshire	NA	NA	NA	NA	NA
New Jersey	0.0	.1	.4	4.8	5.3
New Mexico	0.0	1.5	2.1	13.6	17.2
New York	.2	.4	.5	2.6	3.7
North Carolina	0.0	.3	.5	3.9	4.7
North Dakota	1	.5	3.4	5.9	10.8
Ohio	0.0	0.0	.1	3.2	3.3
Oklahoma	0.0	.8	5.5	22.0	28.3
Oregon	–	–	–	–	–
Pennsylvania	0.0	0.0	.1	1.9	2.0
Rhode Island	0.0	0.0	0.0	.6	0.6
South Carolina	.2	1.6	3.0	10.5	15.3
South Dakota	0.0	1.6	2.4	5.3	9.3
Tennessee	.2	1.7	4.3	8.0	14.2
Texas	0.0	.2	1.3	8.7	10.2
Utah	0.0	.5	1.9	11.6	14.0
Vermont	0.0	0.0	0.0	1.9	1.9
Virginia	0.0	.1	1.6	4.7	6.4
Washington	0.0	.4	1.9	7.2	9.5
West Virginia	0.0	0.0	0.0	3.0	3.0
Wisconsin	.5	1.2	3.1	7.0	11.8
Wyoming	–	–	–	–	–
Total	.2	.6	1.5	6.5	8.8

Note: Specific state data are omitted (–) where the reporting institutions in a specific state housed fewer than two-thirds of the total state institution residents.

Table source: Lakin, Blake, Prouty, Mangan, & Bruininks (1993), Table 1.10

Table 60. Children with Disabilities in Head Start by State: 1989-90

HIGHLIGHTS

- States are mandated by legislation to make available no less than 10% of the total number of enrollment opportunities in Head Start programs to children with disabilities. Children professionally diagnosed as disabled accounted for at least 10% of all Head Start Enrollment in each of the 50 states except Hawaii, with 9.18%.

- Puerto Rico, the Virgin Islands, and the American Indian programs also met the goal. The District of Columbia narrowly missed achieving the 10% requirement, with 9.96%.

EXPLANATORY NOTES

This table is based on data from Head Start Program Information Reports (PIR) which were completed by Head Start programs as of June 30, 1990 and cover program year 1989-90. The data come from 1,321 Head Start full year programs.

Head Start is mandated to serve children with a broad range of disabilities such as those who are mentally retarded, hard of hearing, deaf, speech impaired, visually disabled, seriously emotionally disturbed, or orthopedically impaired. Also included are children with health impairments, or children with specific learning disabilities who require special education and related services.

The statutory definition of children with disabilities excludes from reporting as disabled those children with correctable conditions who do not need special services, or children who will not require services in addition to those which Head Start programs regularly provide. In order to meet this reporting requirement and to ensure that children who are considered disabled are not misdiagnosed, Head Start requires that each child reported as disabled be diagnosed by appropriate professionals.

Table 60. Children with Disabilities in Head Start by State: 1989-90

State	Number of Grantees and Delegate Agencies Reporting	Number of Children Professionally Diagnosed as Disabled	Percent of Enrollment Professionally Diagnosed as Disabled
Alabama	36	1,377	13.01
Alaska	5	146	11.37
Arizona	19	502	12.01
Arkansas	20	959	14.38
California	136	5,191	12.62
Colorado	24	743	14.57
Connecticut	29	537	11.21
Delaware	5	131	12.93
District of Columbia	8	244	9.96
Florida	44	1,697	11.67
Georgia	43	1,662	14.06
Hawaii	6	181	9.18
Idaho	8	259	21.48
Illinois	82	3,022	12.11
Indiana	39	1,350	17.25
Iowa	22	754	17.69
Kansas	23	719	19.37
Kentucky	48	1,854	16.99
Louisiana	44	1,485	13.26
Maine	13	729	28.02
Maryland	28	826	13.91
Massachusetts	34	1,414	15.72
Michigan	81	2,496	10.58
Minnesota	27	1,050	14.17
Mississippi	21	2,804	13.70
Missouri	23	1,521	15.69
Montana	9	286	22.23
Nebraska	16	314	13.57
Nevada	4	99	13.64
New Hampshire	6	115	13.49
New Jersey	33	1,603	15.03
New Mexico	23	539	13.57
New York	150	4,329	15.52
North Carolina	43	1,938	16.77
North Dakota	8	118	15.92
Ohio	77	3,995	16.30
Oklahoma	23	1,296	16.22
Oregon	20	609	16.99
Pennsylvania	66	3,324	17.88
Rhode Island	8	255	13.02
South Carolina	15	908	13.52
South Dakota	7	157	13.52
Tennessee	28	1,450	15.15
Texas	83	3,061	12.01
Utah	11	381	16.34
Vermont	7	150	14.87
Virginia	41	985	15.78
Washington	31	697	13.96
West Virginia	28	695	15.48
Wisconsin	36	948	11.69
Wyoming	5	112	14.51
Puerto Rico	35	2,737	12.73
Virgin Islands	1	188	17.19
Pacific Territories	8	156	4.21
Indian Programs	109	2,152	13.41
Migrant Programs	68	2,055	9.66
Total	1866	69,267	13.29

Note: State data exclude Migrant and Indian Programs
Table source: Head Start Bureau (1992), Appendix C.
Data source: Health Start Program Information Reports, 1989-90

Table 61. Number of Blind and Disabled Children Receiving Federally Administered Supplemental Security Income (SSI) Payments, by State: December 1992

HIGHLIGHTS

- This table provides the state distribution of children who are blind and disabled receiving SSI payments. Nationwide, 98% of SSI child recipients are disabled and 2% are blind.

EXPLANATORY NOTES

The Supplemental Security Income (SSI) program provides income support to persons aged 65 and older, blind or disabled adults, and blind or disabled children. Eligibility requirements and federal payment standards are nationally uniform. The program is administered by the Social Security Administration.

To be eligible for SSI payments as a child, an individual must be under age 18 (or under age 22 if he or she is a full-time student), unmarried, and must meet applicable disability, income and resource criteria.

Table 61. Number of Blind and Disabled Children Receiving Federally Administered Supplemental Security Income (SSI) Payments, by State: December 1992

State	Total	Blind	Disabled
Total	623,845	9,402	614,443
Alabama	18,281	124	18,157
Alaska	568	16	552
Arizona	7,515	119	7,396
Arkansas	13,288	149	13,139
California	50,074	1,809	48,265
Colorado	6,378	74	6,304
Connecticut	3,613	88	3,525
Delaware	1,258	14	1,244
District of Columbia	1,645	12	1,633
Florida	31,705	319	31,386
Georgia	18,565	249	18,316
Hawaii	665	18	647
Idaho	2,784	38	2,746
Illinois	31,874	299	31,575
Indiana	14,118	193	13,925
Iowa	5,793	168	5,625
Kansas	5,278	66	5,212
Kentucky	14,152	171	13,981
Louisiana	28,708	247	28,461
Maine	1,924	35	1,889
Maryland	7,257	79	7,178
Massachusetts	10,994	556	10,438
Michigan	23,245	254	22,991
Minnesota	6,054	163	5,891
Mississippi	17,532	90	17,442
Missouri	14,381	151	14,230
Montana	1,521	20	1,501
Nebraska	2,865	40	2,825
Nevada	1,639	80	1,559
New Hampshire	1,034	11	1,023
New Jersey	14,803	127	14,676
New Mexico	4,380	61	4,319
New York	52,793	393	52,400
North Carolina	18,432	265	18,167
North Dakota	892	18	874
Ohio	29,198	427	28,771
Oklahoma	8,130	162	7,968
Oregon	4,694	104	4,590
Pennsylvania	28,896	314	28,582
Rhode Island	1,765	30	1,735
South Carolina	11,223	200	11,023
South Dakota	1,999	25	1,974
Tennessee	16,018	218	15,800
Texas	40,520	733	39,787
Utah	3,106	84	3,022
Vermont	1,010	19	991
Virginia	12,449	200	12,249
Washington	7,567	125	7,442
West Virginia	6,007	100	5,907
Wisconsin	14,408	132	14,276
Wyoming	773	13	760
Other: Northern Mariana Islands	64	--	64
Unknown	10	--	10

Table source: Social Security Administration (1993), Table 7.B8

Table 62. Children Served by State Protection and Advocacy for Individuals with Mental Illness (PAIMI), by Age and State: Fiscal Year 1992

HIGHLIGHTS

- In fiscal year 1992, PAIMI programs served 20,379 clients. Several states designated services to children and youths as a program priority, and 2,273 (11%) of the PAIMI programs clients were younger than age 21.

EXPLANATORY NOTES

These data are provided by State Protection and Advocacy for Individuals with Mental Illness (PAIMI) programs to the Center for Mental Health Services (CMHS), part of the Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services. The data are provided in fulfillment of reporting requirements under the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

The PAIMI act of 1986 authorizes formula grants to Protection and Advocacy systems to protect the rights of and advocate for individuals with disabilities. The grants awarded by CMHS are to be used to pursue administrative, legal, and other appropriate remedies to redress complaints of abuse, neglect, and rights violations and to protect and advocate the rights of individuals with mental illness to ensure the enforcement of the Constitution, and federal and state statutes.

Table 62. Children Served by State Protection and Advocacy for Individuals with Mental Illness (PAIMI), by Age and State: Fiscal Year 1992

State	Age		
	0 - 4	5 - 20	0 - 20
Alabama	0	0	0
Alaska	0	25	25
Arizona	0	21	21
Arkansas	0	4	4
California	0	157	157
Colorado	0	22	22
Connecticut	0	6	6
Delaware	0	5	5
District of Columbia	0	20	20
Florida	0	11	11
Georgia	0	19	19
Guam	0	2	2
Hawaii	0	16	16
Idaho	0	25	25
Illinois	0	135	135
Indiana	0	22	22
Iowa	0	2	2
Kansas	0	16	16
Kentucky	30	152	182
Louisiana	0	19	19
Maine	0	37	37
Maryland	0	38*	38
Massachusetts	0	45	45
Michigan	0	92	92
Minnesota	7	62	69
Mississippi	0	6	6
Missouri	0	37	37
Montana	0	58	58
Nebraska	0	42	42
Nevada	0	32	32
New Hampshire	0	76	76
New Jersey	0	142	142
New Mexico	3	40	43
New York	0	244	244
North Carolina	0	96	96
North Dakota	0	31	31
Ohio	0	100	100
Oklahoma	0	11	11
Oregon	0	15	15
Pennsylvania	0	20	20
Puerto Rico	0	0	0
Rhode Island	0	5	5
South Carolina	0	93	93
South Dakota	0	3	3
Tennessee	0	19	19
Texas	8	72	80
Utah	2	23	25
Vermont	1	1	2
Virgin Islands	0	1	1
Virginia	0	50	50
Washington	0	12	12
West Virginia	0	7	7
Wisconsin	0	24	24
Wyoming	0	9	9
Total	51	2222	2273

* Ages 5 to 17.

Table source: Center for Mental Health Services (1992), Table 2.

INVENTORY OF DATA SOURCES

ANNUAL SURVEY OF DEAF AND HARD-OF-HEARING CHILDREN AND YOUTH

AGENCY	Gallaudet University Center for Assessment and Demographic Studies (CADS)
ADDRESS	800 Florida Avenue, N.E. Washington, DC 20002
CONTACT	Arthur N. Schildroth Sue Hotto
PHONE	202-651-5575 800-451-8834, Ext. 5575 FAX: 202-651-5746
FUNDING SOURCE	Gallaudet University
FREQUENCY OF DATA COLLECTION	Annually
DATES OF COVERAGE	1968 to present
DESCRIPTION OF SURVEY	The survey is mailed annually to all special educational programs enrolling deaf and hard-of-hearing students. Directors of special education in the states are contacted each year in an effort to update the survey mailing list. If the child count numbers reported to the federal government by the states each year are accurate, then the Annual Survey includes approximately 60% of all deaf and hard-of-hearing children receiving special educational services in the United States. For the 1992-93 school year, a total of 48,300 students were reported to the Annual Survey.
EVALUATION OF SURVEY	The survey is voluntary and does not include all hearing-impaired students in special education.

SURVEY VARIABLES

Age	Date of birth
Sex	Male, female
Ethnicity	White (non-Hispanic), Black (non-Hispanic), Hispanic, American Indian, Asian/Pacific, other, multi-ethnic background
Region	Northeast, Midwest, South, West
Age at onset of hearing loss	At birth, under one year, exact age
Probable cause of hearing loss	Causes at birth: maternal rubella; trauma at birth; other complications of pregnancy; heredity, prematurity; cytomegalovirus; RH incompatibility; other cause at birth Causes after birth: meningitis; high fever; mumps; infection; measles; otitis media; trauma after birth; other cause after birth
Additional handicapping conditions	Defined as educationally significant handicapping condition in addition to hearing impairment
Primary method of teaching	Auditory/oral only; sign and speech; sign only; cued speech
Interpreter provided	Yes/no, teacher interprets; type of interpreter (sign, oral, cued speech)
Degree of hearing loss	Actual audiological test results; estimate of six-category scale from within normal limits to profound

Fluctuating or unilateral hearing loss	Yes/no
Cochlear implant	Yes/no; date of implant
Special education classroom instruction received	Yes/no
Type of facility	Residential school for the deaf, day school for the deaf, speech and hearing clinic/ regular education facility for hearing students
Hours per week classroom academic integration with hearing students	None; 1 to 5; 6-10; 11-15; 16 or more

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Limited by confidentiality requirements. Consult the Center for Assessment and Demographic Studies at Gallaudet University.
REPORTS	Schildroth, A. N., & Hotto, S. A. (1993). Annual survey of hearing-impaired children and youth: 1991-92 school year. American Annals of the Deaf, 138, 163-171. Schildroth, A., & Karchmer, M. (Eds.). (1986). Deaf children in America. Austin, TX: College-Hill. Allen, T., Rawlings, B., & Schildroth, A. (1989). Deaf students and the school-to-work transition. Baltimore, MD: Paul Brookes.

BIRTH DEFECTS MONITORING PROGRAM (BDMP)	
AGENCY	Centers for Disease Control and Prevention (CDC)
ADDRESS	Birth Defects and Genetic Diseases Branch Division of Birth Defects and Developmental Disabilities Center for Environmental Health and Injury Control Centers for Disease Control and Prevention Atlanta, GA 30333
CONTACT	Larry D. Edmonds
PHONE	404-488-7170
FUNDING SOURCE	Centers for Disease Control and Prevention
FREQUENCY OF DATA COLLECTION	Quarterly
DATES OF COVERAGE	1974 to present
DESCRIPTION OF SURVEY	The Birth Defects Monitoring Program (BDMP) is a national surveillance program in which researchers monitor and analyze hospital discharge data for birth defects and other newborn conditions. The BDMP was initiated at the Centers for Disease Control and Prevention in December 1974. The BDMP includes two separate databases, both derived from discharge information that participating hospitals send to health-data processing systems. The two health data processing systems receiving hospital data are the Commission on Professional and Hospital Activities (CPHA) and the McDonnell Douglas Health Information System (MDHIS); these two systems operate in a similar manner. Discharge abstracts are coded by hospital medical records personnel and submitted regularly to CPHA or MDHIS for processing. The major difference between the two systems is that stillbirths are excluded from the data CDC obtains from MDHIS. The BDMP/CPHA was the sole source of newborn data for the BDMP from 1974 until 1984. In September 1984, the Division of Chronic Disease Control and the Division of Birth Defects and Developmental Disabilities of the Center for Environmental Health and Injury Control started a program to monitor chronic diseases through the Nationwide Monitoring Program. The data for this program were obtained from the MDHIS through 1988. Approximately 1,200 hospitals, most of which are midsize community hospitals, have granted use of their data. From 1988 through 1991, 1,808,225 births were monitored, or 11.2% of all U.S. births.
EVALUATION OF SURVEY	Some 161 defect categories are analyzed to identify unusual trends and geographic differences within the CPHA and MDHIS data. The data are reviewed four times a year, and defects are usually reported 3-6 months after an affected infant's birth. Although these data sources are not population based and are not a random sample of U.S. births, they represent the largest single set of uniformly collected and coded discharge data on birth defects among newborns in the United States.

SURVEY VARIABLES	
Sex	Male, female
Ethnicity	White, other
Geographic region	Northeast, North Central, South, West
Congenital malformation	161 categories including major categories of: central nervous system, eye, cardiovascular, orofacial, gastrointestinal, genitourinary, musculoskeletal, and chromosomal

AVAILABILITY OF DATA	
TAPES AND DOCUMENTATION	Not available
REPORTS	Centers for Disease Control (1988, March). Congenital malformations surveillance report, January 1982-December 1985). Atlanta, GA: U.S. Department of Health and Human Services. Centers for Disease Control and Prevention (1993). Congenital malformations surveillance. Atlanta, GA: U.S. Department of Health and Human Services. Reprinted from Teratology, 48, 545-709 (December 1993).

ELEMENTARY AND SECONDARY SCHOOL CIVIL RIGHTS SURVEY, 1990

AGENCY	Office for Civil Rights (OCR) Surveys and Statistical Support Branch U.S. Department of Education
ADDRESS	330 C Street, N.W. Washington, DC 20202
CONTACT	Sharon Tuchman
PHONE	202-205-9584
FUNDING SOURCE	Office for Civil Rights
FREQUENCY OF DATA COLLECTION	Biennially
DATES OF COVERAGE	1967-68 school year through present
DESCRIPTION OF SURVEY	The Office for Civil Rights (OCR) Elementary and Secondary School Civil Rights Survey has been conducted on a national basis beginning with the 1967-68 school year. The information is required by the OCR to fulfill its responsibilities under Title VI of the Civil Rights Act of 1964, Title IX of the Education Amendments of 1972, and Section 504 of the Rehabilitation Act of 1973. These laws prohibit discrimination on the basis of race, national origin, handicap, sex, and age. The survey instrument contains two forms: a district level form (ED101) and a school level form (ED102). Each district selected to participate in the survey completes an ED101 form. Every school within selected districts completes an ED102 form. However, districts with more than 100 schools were given the option to subsample schools. For the 1990 survey, which covered the 1989-90 school year, a stratified random sample of 3,434 districts containing 40,025 schools was drawn.
EVALUATION OF SURVEY	Districts sometimes initially submitted incomplete, inaccurate, or inconsistent data. Despite a major effort to secure additional information or corrected data from the districts, some errors remain. In particular, some districts reported totals which did not agree with computed totals by race/ethnicity and sex.

SURVEY VARIABLES

Special education at district level	Number of children: awaiting initial evaluation identified as requiring special education receiving special education in the district receiving special education in a nondistrict facility
Ethnicity	White, not of Hispanic origin; Black, not of Hispanic origin; Hispanic, American Indian or Alaskan Native; Asian or Pacific Islander
Sex	Male, female
School enrollment	As of October 1
Suspensions	Students suspended for at least one day during the school year

Corporal punishment	Students who received corporal punishment during the school year
Gifted/talented	Number of students in programs for gifted or talented, by race and sex
Special education programs	Number of students in programs for educable mentally retarded, trainable mentally retarded, hard of hearing, deaf, speech impaired, visually impaired, seriously emotionally disturbed, orthopedically impaired, other health impaired, specific learning disability, deaf/blind, and multihandicapped. The categories of educable mentally retarded, trainable mentally retarded, speech impaired, seriously emotionally disturbed, and specific learning disability were the only categories for which race and sex were reported.
Single-sex classes	Number of students enrolled in home economics, industrial arts, and physical education courses that are single sex or mixed.
Graduates	Number of students who received a regular high school diploma during the school year by race and sex.

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Available upon written request to: Office for Civil Rights Surveys and Statistical Support Branch U.S. Department of Education 330 C Street, S.W. Washington, DC 20202 Phone: 202-205-8616
REPORTS	Office for Civil Rights (1993). Fall 1990 elementary and secondary school civil rights survey: Revised national statistical estimates. Washington, DC: U.S. Department of Education.

HEAD START PROGRAM INFORMATION REPORT (PIR)

AGENCY	Head Start Bureau
ADDRESS	Administration on Children, Youth and Families Administration for Children and Families U.S. Department of Health and Human Services 330 C Street, S.W. Washington, DC 20201
CONTACT	Jim O'Brien Program Specialist
PHONE	202-205-8213
FUNDING SOURCE	Head Start Bureau
FREQUENCY OF DATA COLLECTION	Annually
DATES OF COVERAGE	1972-73 through present
DESCRIPTION OF SURVEY	The PIR data were collected by the Administration for Children and Families regional offices. The PIR was mailed to all Head Start grantees and delegate agencies in May 1990. Head Start programs reported on the status of children with disabilities as of June 30, 1990, or the end of their program year. The entire population (N=1,866) of Head Start grantees completed the 1989-90 program year PIR which provides information about children with disabilities. Data in the annual report are based on responses from 1,321 Head Start full year programs. Nearly all Programs are full year that operate 8 to 12 months of the year. Thirty-seven Parent and Child Centers (designed to serve children from birth to three years of age and their families) were included in the 1989-90 PIR. Head Start served 521,266 children. Of these, 69,267 (13.3%) were children with disabilities. To be counted as disabled in Head Start, children must meet two criteria. They must have a disabling condition as determined by professional diagnosis, and require special education and related services because of the disabling condition.

SURVEY VARIABLES

Age	Date of birth
Disabling condition	Blindness, visual impairment, deafness, hearing impairment, physical disability, speech impairment, health impairment, mental retardation, serious emotional disturbance, or special learning disability
Multiple disabilities	Children are reported as having multiple disabilities when, in addition to their primary or most disabling condition, one or more other disabling conditions are present
Location	State, District of Columbia, Puerto Rico, Virgin Islands, Pacific Territories, Indian Programs, and Migrant Programs
Staff	Number of programs with full or part-time coordinators of services for children with disabilities; type of degrees or licenses held

Enrollment	Number of children with disabilities located by and referred to Head Start programs, who could not be enrolled Number of children professionally diagnosed who dropped out Number who underwent diagnosis and were found not to be disabled
Services	Recruitment, outreach, assessment, diagnosis, mainstreaming, special services, and coordination with other agencies

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Dennis Mulligan Head Start Bureau U.S. Department of Health and Human Services 330 C Street, S.W. Washington, DC 20201 Phone: 202-205-8574
REPORTS	The status of children with disabilities in Head Start programs: Eighteenth annual report of the U.S. Department of Health and Human Services to the Congress of the United States on services provided to children with disabilities in the Head Start program. (1992). Washington, DC: Head Start Bureau, Department of Health and Human Services.

HIV/AIDS SURVEILLANCE

AGENCY	Centers for Disease Control and Prevention (CDC)
ADDRESS	Department of Health and Human Services Public Health Service Centers for Disease Control and Prevention Atlanta, GA 30333
CONTACT	Russ P. Metler Surveillance Report Coordinator
PHONE	404-639-2050
FUNDING SOURCE	Centers for Disease Control and Prevention
FREQUENCY OF DATA COLLECTION	Ongoing. Quarterly surveillance reports include information received and tabulated by CDC through the last day of the previous quarter.
DATES OF COVERAGE	June 1982 to present
DESCRIPTION OF SURVEY	All 50 states, the District of Columbia, U.S. dependencies and possessions report AIDS cases to CDC using a uniform case definition and case report form.
EVALUATION OF SURVEY	Reporting delays (time between diagnosis and report to CDC) vary widely among exposure, geographic, racial/ethnic, and age categories, and have been as long as several years for some cases. About 55% of all cases are reported within 3 months of diagnosis, but about 20% are reported more than one year after diagnosis.

SURVEY VARIABLES

Age at diagnosis of AIDS	Pediatric (younger than 13 years); Adult/adolescent (13 years and older)
Sex	Male, female
Ethnicity	White, not Hispanic; Black, not Hispanic; Hispanic; American Indian/Alaska Native; Asian/Pacific Islander
Place of residence	State, District of Columbia, Puerto Rico, Virgin Islands, Guam, and U.S. Pacific islands
Metropolitan area of residence	Metropolitan areas with 500,000 or more population; metropolitan areas with 50,000 to 499,999 population; non-metropolitan areas
Rates	Calculated on an annual basis per 100,000 population, based on U.S. Bureau of Census data from the 1990 census and on extrapolations from the 1990 census and official Census Bureau estimates for 1991. Each 12-month rate is the number or cases for a 12-month period divided by the 1991 or 1992 population, multiplied by 100,000.
Exposure category for pediatric AIDS cases	Hemophilia/coagulation disorder; mother with/at risk for HIV infection; receipt of blood transfusion, blood components, or tissue

AVAILABILITY OF DATA	
TAPES AND DOCUMENTATION	AIDS Public Information Data Set is available on 3.5 inch diskette in DOS/ASCII format. The Dataset includes information reported in the Surveillance Report. Diana Mazzella Centers for Disease Control and Prevention Mailstop E-48 1600 Clifton Road NE Atlanta, GA 30333 Phone: 404-639-2050
REPORTS	Centers for Disease Control and Prevention (1993, May). HIV/AIDS Surveillance Report, 5. Atlanta, GA: U.S. Department of Health and Human Services.

INVENTORY OF MENTAL HEALTH ORGANIZATIONS AND GENERAL HOSPITAL MENTAL HEALTH SERVICES (IMHO/GHMHS)

AGENCY	Center for Mental Health Services Substance Abuse and Mental Health Services Administration Public Health Service U.S. Department of Health and Human Services
ADDRESS	5600 Fishers Lane Rockville, MD 20857
CONTACT	Michael Witkin
PHONE	301-443-3343
FUNDING SOURCE	Center for Mental Health Services
FREQUENCY OF DATA COLLECTION	Biennial
DATES OF COVERAGE	1970-1988
DESCRIPTION OF SURVEY	Before 1986, the Inventory of Mental Health Organizations and Inventory of General Hospital Mental Health Services (IGHMHS) functioned as separate, 100% enumeration surveys designed to collect information on specialty mental health organizations in the United States. The IGHMHS covered psychiatric services of general hospitals, while the IMHO covered other specialty mental health organizations, including State and county mental hospitals, private psychiatric hospitals, and psychiatric outpatient clinics. Beginning in 1986, the IMHO-GHMHS was designed to simplify data collect procedures and response burden. Because similarities existed between the questions asked in the previously conducted separate inventories, a common core form with three versions was developed: one for specialty mental health organizations, one for general hospitals with separate psychiatric services, and a brief screening form for general hospitals without separate psychiatric services. Since the survey was carried out with a common core form, comparable information was obtained from general hospitals at the same time as from other specialty mental health organizations. In 1988, there were 440 residential treatment centers (RTCs) that provided services to approximately 23,000 emotionally disturbed children.
EVALUATION OF SURVEY	Data for the five most recent years are influenced by factors that affect the comparability of data among these years and earlier years. The large increase in the number of Residential Treatment Centers for Emotionally Disturbed Children between 1983 and 1988 was attributed to the identification of RTCs from lists obtained on RTCs in 1986 which were previously unknown.

SURVEY VARIABLES

Type of services provided	Inpatient, outpatient, and partial care
Type of organization	Outpatient mental health clinic, psychiatric hospital, residential treatment center for emotionally disturbed children (RTC), mental health partial care organization, multiservice mental health organization, general hospital with separate psychiatric service

Other	Number of inpatient beds; number of inpatient, outpatient, and partial care additions; average daily and end of year inpatient census; expenditures; revenue by source; and staffing by type of discipline

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Available upon written request to: Ronald W. Manderscheid, Ph.D. Survey and Analysis Branch Center for Mental Health Services Substance Abuse and Mental Health Services Administration U.S. Department of Health and Human Services 5600 Fishers Lane Rockville, MD 20857
REPORTS	Redick, R. W., Witkin, M. J., Atay, J. E., & Manderscheid, R. W., (1992). Specialty mental health system characteristics. In R. W. Manderscheid & M. A. Sonnenschein (Eds.), Mental Health, United States, 1992 (DHHS Publication No. SMA 92-1942). Washington, DC: U.S. Government Printing Office. Redick, R. W., Witkin, M. J., Atay, J. E., & Manderscheid, R. W. (1993, April). Staffing of mental health organizations, United States, 1988. Statistical Note No. 206. Rockville, MD: U.S. Department of Health and Human Services. Sunshine, J. H., Witkin, M. J., Atay, J. E., & Manderscheid, R. W. (1992, July). Partial care in mental health organizations: United States and each state, 1988. Statistical Note No. 205. Rockville, MD: U.S. Department of Health and Human Services. Redick, R. W., Witkin, M. J., Atay, J. E., & Manderscheid, R. W. (1992, May). Patient care episodes in mental health organizations, United States: Selected years from 1955 to 1988. Statistical Note No. 204. Rockville MD: U.S. Department of Health and Human Services.

NATIONAL INFORMATION AND REPORTING SYSTEM (NIRS)

AGENCY	American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)
ADDRESS	8630 Fenton Street Suite 410 Silver Spring, MD 20910
CONTACT	Roland Loudenburg
PHONE	301-588-8252
FUNDING SOURCE	Administration on Developmental Disabilities and Maternal and Child Health Bureau U.S. Department of Health and Human Services
FREQUENCY OF DATA COLLECTION	Annually
DATES OF COVERAGE	Most recently available: July 1, 1990 through June 31, 1991
DESCRIPTION OF SURVEY	Data are collected from University Affiliated Programs (UAP) for Persons with Developmental Disabilities. The most recent data are for UAP activities for the period from July 1, 1990 through June 31, 1991. Each UAP is required to report data on the following program activities: funding, interdisciplinary training, university classroom training, community based clients, UAP clinic-based clients, outreach training/technical assistance, and UAP developed products. The dataset on UAP clinic-based clients includes information about individual clients and families who received direct services from UAPs. UAP clients are individuals who receive direct services from UAP facility, staff, or interdisciplinary teams during the report period, regardless of the date the case was first opened by the UAP. To be classified as a UAP client, individuals must meet the following criteria: 1. the individuals received direct services from the UAP faculty, staff, or trainee; 2. the UAP has control over the individual's treatment chart; and 3. the UAP is legally responsible for maintaining the client's chart. Confusion often arises regarding the definition of UAP Client and Community-Based Client Contacts. UAP Clients are those who receive evaluations and direct services in UAP clinics and/or through UAP interdisciplinary teams. UAP is the primary repository of the client's records and is legally responsible for maintaining them. Community-Based Client Contacts are services provided to clients who are not considered UAP clients because a non-UAP program is legally responsible for the client. The NIRS database includes 44,741 children and youth ages 0 through 21.
EVALUATION OF SURVEY	The database includes characteristics of UAP programs, their funding sources, and the number of clients served.

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SURVEY VARIABLES

Age	Date of birth
Sex	Male, female
Ethnicity	White, Black, Hispanic, Asian, American Indian
Referral source	Physician, public health, mental health, hospital, social services, school, state MR/DD, community agency, self/family, other
Primary diagnosis	Mental retardation, autism, cerebral palsy, motor disorder, communication disorder, learning disorder, behavior disorder, visual impairment, hearing impairment, epilepsy, psychiatric disorder, multiple handicaps, chronic illness, genetic disorder, other

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Available upon request from: Roland Loudenburg American Association of University Affiliated Programs 8630 Fenton Street Suite 410 Silver Spring, MD 20910 Phone: 301-588-8252 FAX: 301-588-2842
REPORTS	<u>NIRS data reference guide - 1991.</u> (1991). Silver Spring, MD: American Association of University Affiliated Programs for Persons with Developmental Disabilities.

NATIONAL HEALTH INTERVIEW SURVEY

AGENCY	National Center for Health Statistics U.S. Department of Health and Human Services
ADDRESS	6525 Belcrest Road, Room 850 Hyattsville, MD 20782
CONTACT	Gerry E. Hendershot, Ph.D. Chief, Illness and Disability Statistics Branch
PHONE	301-436-7085
FUNDING SOURCE	National Center for Health Statistics
FREQUENCY OF DATA COLLECTION	Continuing, with weekly samples
DATES OF COVERAGE	1957 to present. Data from the 1991 survey are the most recently available.
DESCRIPTION OF SURVEY	The National Health Interview Survey (NHIS) is a continuing nationwide survey by household interview. Each week a probability sample of the civilian noninstitutionalized population of the United States is interviewed by personnel of the U.S. Bureau of the Census. Information is obtained about the health and other characteristics of each member of the household. The 1991 NHIS was conducted with a full sample. The interviewed sample for 1991 consisted of 46,761 households containing 120,032 persons. The total noninterview rate was 4.3%; 2.7% was the result of respondent refusal and the remainder was due to failure to locate an eligible respondent at home after repeated calls. All information collected in the survey is from reports by responsible family members residing in the household. When possible, all adult family members participate in the interview. However, proxy responses are accepted for family members who are not at home and are required for all children and for family members who are physically or mentally incapable of responding for themselves. The information from both proxy respondents and self-respondents may be inaccurate because the respondent is unaware of relevant information, has forgotten it, does not wish to reveal it to an interviewer, or because the respondent does not understand the intended meaning of the question. The estimates presented in the 1991 report are based upon 1991 sample person counts weighted to produce national estimates. The weight for each sample person is the product for four component weights: (1) probability of selection, (2) household nonresponse adjustment within segment, (3) first-stage ratio adjustment, and (4) poststratification by age/sex/race.
EVALUATION OF SURVEY	NHIS uses various reference periods to reduce the amount of bias associated with respondent memory loss. Chronic condition prevalence estimates are based on a 12-month reference period. Sampling error is the variation that might occur by chance because only a sample of the population is surveyed. The standard error is a measure of sampling error. Individual standard errors were not computed for each estimate in the 1991 report. Instead, standard errors were computed for a broad spectrum of estimates. Regression techniques were then applied to produce equations from which a standard error for any estimate can be approximated by the data user.

SURVEY VARIABLES

Age	Age at last birthday
Sex	Male, female
Ethnicity	White, black, all other (Aleut, Eskimo, American Indian, Asian, Pacific Islander)
Family income	Total of all income from all sources received by members of the family in the 12-month period preceding the week of interview
Place of residence	Metropolitan statistical area (MSA), central city; MSA, not central city; not MSA
Geographic region	Northeast, Midwest, South, West
Chronic condition	A condition is considered chronic if (a) the respondent indicates it was first noticed more than 3 months before the date of the interview, or (b) it is a type of condition that ordinarily has a duration of more than 3 months
Limitation of activity	A long-term reduction in a person's capacity to perform the average kind or amount of activities associated with his or her age group. For children, the major activities are: (a) ordinary play for children under 5 years of age; (b) attending school for those 5-17 year old; and (c) working or keeping house for persons 18-69
Assessed health status	Excellent, very good, good, fair, poor

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	See: National Center for Health Statistics (July 1992). Catalog of electronic data products. Hyattsville, MD: Author. Public use tapes for NHIS surveys from 1969 through 1991: National Technical Information Service 5285 Port Royal Road Springfield, VA 22161 Public use tapes for special topics included in NHIS from 1973 through 1991: National Center for Health Statistics Division of Health Interview Statistics Systems and Programming Branch 6525 Belcrest Road Hyattsville, MD 20782 CD-ROM is available for the 1987 NHIS. Tapes are accompanied by documentation including tape content, Interviewers' Manual, medical coding instructions, sample tabulation specifications, and related final data tables from publications.
REPORTS	Adams, P. F., & Benson, V. (1992). Current estimates from the National Health Interview Survey, 1991. Series 10, No. 184. Hyattsville, MD: National Center for Health Statistics. Ries, P., & Brown, S. (1991). Disability and health: Characteristics or persons by limitation of activity and assessed health status, United States, 1984-88. Advance data from vital and health statistics, No. 197. Hyattsville, MD: National Center for Health Statistics.

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

AGENCY	National Center for Health Statistics U.S. Department of Health and Human Services
ADDRESS	6525 Belcrest Road, Room 850 Hyattsville, MD 20782
CONTACT	Charlotte A. Schoenborn Division of Health Interview Statistics
PHONE	301-436-7085
FUNDING SOURCE	Office of Maternal and Child Health The National Institute of Child Health and Human Development The National Center for Health Statistics
DATES OF COVERAGE	1988
DESCRIPTION OF SURVEY	The National Health Interview Survey (NHIS) is an ongoing survey of households in the United States conducted by the National Center for Health Statistics. Each week, a probability sample of the civilian noninstitutionalized population of the United States is interviewed by personnel of the U.S. Bureau of the Census. Interviewers obtain information about the health and other characteristics of each member of the households included in the NHIS sample. NHIS consists of two parts (a) a basic health questionnaire that remains the same each year and is completed for each household member and (b) special topics questionnaires that vary from year to year and usually are asked of just one person in each family. In 1988, the special topics included child health. The total sample interviewed for 1988 for the basic health questionnaire consisted of 47,485 households containing 122,310 individuals. The total response rate was 95%. For the National Health Interview Survey on Child Health (NHIS-CH), one sample child under the age of 17 years was selected from each family with children in that age range. Information about the sample child was collected by face-to-face interview with the adult member of the family present who knew most about the sample child's health, in most cases the mother. Interviews were completed for 17,110 children 17 years of age and under, 95% of those identified as eligible on the basis of the basic health questionnaire. The overall response rate for NHIS-CH was 91%, the product of the response rates for the basic and the child health questionnaire.
EVALUATION OF SURVEY	Data on developmental, learning, and behavioral disorders were obtained from parental reports. This may result in underestimating the prevalence of these conditions because parents sometimes do not accept or understand the assessments of teachers or health professionals. In some cases, parents may have forgotten problems that occurred in the past, or results were not communicated clearly to parents.

SURVEY VARIABLES	
Age	Date of birth
Sex	Male, female
Ethnicity	White, Black, Hispanic
Family income	Total of all income from all sources received by members of the family in the 12-month period preceding the week of interview
Place of residence	Metropolitan statistical area (MSA), central city; MSA, not central city; not MSA.
Mother's education	Years of school completed
Family structure	Biological mother and father; biological mother and stepfather; biological mother only; other
Developmental delay	Whether the child ever had a delay in growth or development
Learning disability	Whether the child ever had a learning disability. Asked only about children ages 3 years and over
Emotional or behavioral problem	Whether the child ever had an emotional or behavioral problem that lasted 3 months or more. Whether the child has ever seen a psychiatrist, psychologist, doctor or counselor about any emotional, mental, or behavioral problem. Whether the parent has felt or anyone has suggested that the child needed help for any emotional, mental or behavioral problem. Asked only about children ages 3-17.
Other	When condition was first noticed, whether the child was treated for the condition (ever and in the last 12 months), the effects of the condition on school attendance, need for special education, and whether any medication was taken for the condition.

AVAILABILITY OF DATA	
TAPES AND DOCUMENTATION	National Center for Health Statistics Division of Health Interview Statistics Systems and Programming Branch 6525 Belcrest Road Hyattsville, MD 20782
REPORTS	Zill, N., & Schoenborn, C. A. (1990). Developmental, learning, and emotional problems: Health of our nation's children, United States, 1988. Advance data from vital and health statistics; No. 190. Hyattsville, MD: National Center for Health Statistics. Aday, L. (1992). Health insurance and utilization of medical care for chronically ill children with special needs. Advance data from vital and health statistics; no. 215. Hyattsville, MD: National Center for Health Statistics.

NATIONAL LONGITUDINAL SURVEY OF YOUTH (NLSY)

AGENCY	Center for Human Resource Research The Ohio State University
ADDRESS	921 Chatham Lane, Suite 200 Columbus, OH 43221
CONTACT	Paula C. Baker
PHONE	614-442-7375
FUNDING SOURCE	Bureau of Labor Statistics, U.S. Department of Labor National Institute of Child Health and Human Development
FREQUENCY OF DATA COLLECTION	Interviews are annually; child assessment and health status information is biennially.
DATES OF COVERAGE	1979-1993
DESCRIPTION OF SURVEY	The National Longitudinal Survey of Youth (NLSY) is a multipurpose survey of more than 12,600 individuals who have been interviewed annually since 1979 when they were 14 to 21 years of age. Sponsored by the Department of Labor, the NLSY contains extensive information about the employment, education, training, and family-related experiences of the respondents. Since 1982, through support of the National Institute of Child Health, questions have been asked about pregnancy and post-natal histories, fertility, and child care usage. In 1986, 1988, 1990, and 1992 the children of mothers in the sample were administered a series of assessments designed to measure cognitive ability, temperament, motor and social development, behavior problems, perceived competence, and quality of the home environment. This assessment information has been combined with data from the mothers' records to form a detailed data file for users interested in exploring the interrelationships between family and environmental factors, maternal behavior and child development. The National Opinion Research Center at the University of Chicago collects the data; the Center for Human Resource Research (CHRR) at The Ohio State University prepares public use materials and disseminates reports which utilize the NLSY data. The Child Health section of the Child Supplement collects information from the mother on the child's health limitations, accidents and injuries, medical treatment in the last twelve months, and health insurance coverage. The women in the 1990 sample represent a national cross-section of mothers who were between the ages of 25 and 32 on January 1, 1990. The children in the sample represent approximately the first two-thirds childbearing for that cohort of women and should not be considered representative of all American children. The children of the sampled women are representative of American children who have been born to American mothers 25 to 32 years of age on January 1, 1990.
EVALUATION OF SURVEY	The large sample of black, Hispanic and economically disadvantaged white women and children permit the analysis of program-relevant groups. The NLSY includes a wide range of family background, education, employment, income and attitudinal data. The younger children in the sample are substantially more likely to be white, to have been born to older mothers, and even after controlling for race/ethnicity, to have more educated mothers.

SURVEY VARIABLES

Age	Date of birth
Sex	Male, female
Ethnicity	White, Black, Hispanic
Physical, emotional, or mental conditions	Limits or prevents regular school attendance; limits or prevents ability to do regular school work; limits or prevents usual childhood activities such as play, or participate in games or sports; requiring frequent attention or medical treatment; requiring regular use of medicine; or requiring use of special equipment
Health conditions	Learning disability; minimal brain dysfunction; cerebral dysfunction; attention deficit disorder; hyperkinesis; asthma; respiratory disorder; speech impairment; serious hearing difficulty or deafness; serious difficulty in seeing or blindness; serious emotional disturbance; allergic conditions; orthopedic handicap; mental retardation; heart trouble; chronic nervous disorder; chronic ear problems; blood disorder or immune deficiency; epilepsy; other
Duration of limitation	All his/her life; less than one year; number of years
Child residence	With mother, with father, elsewhere

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	NLSY Child data are currently available on both magnetic tape and on CD-ROM. One set of hardcopy documentation has been prepared for data tape purchasers, and another for CD-ROM users. Select documentation items such as codebooks and numerics are also provided on the data tapes themselves. As of the 1990 release, CD-ROM users currently receive the 1986-1990 Child Data as well as the entire 1979-1991 NLSY longitudinal record for females on disc. The CD-ROM also contains variable descriptions and codebook information for the entire NLSY record, the child assessment items, and the constructed child variables. Steve McClaskie NLS User Services Center for Human Resource Research 921 Chatham Lane, Suite 200 The Ohio State University Columbus, OH 43221-2418 Phone: 614-442-7366 FAX: 614-442-7329 BITNET: USERSVC@OHSTHR.BITNET Internet:usersvc@pewter.chrr.ohio-state.edu
REPORTS	Baker, P. C., Keck, C. K., Mott, F. L., & Quinlan, S. V. (1993). NLSY child handbook, revised ed.: A guide to the 1986-1990 National Longitudinal Survey of Youth, Child Data. Columbus, OH: Center for Human Resource Research, The Ohio State University. Mott, F. L., & Quinlan, S. V., (1991). Maternal-child health data from the NLSY: 1988 tabulations and summary discussion. Columbus, OH: Center the Human Resource Research, The Ohio State University.

NATIONAL LONGITUDINAL TRANSITION STUDY OF SPECIAL EDUCATION STUDENTS (NLTS)

AGENCY	Office of Special Education Programs U.S. Department of Education
ADDRESS	Switzer Building 330 C Street, S. W. Washington, DC 20202
CONTACT	Scott Brown
PHONE	202-205-8117
FUNDING SOURCE	Office of Special Education Programs U.S. Department of Education
FREQUENCY OF DATA COLLECTION	1987 (telephone interview with parent), 1989 (subsample interview), 1990 (parent and/or youth interview)
DATES OF COVERAGE	1987-1990
DESCRIPTION OF SURVEY	The purpose of the NLTS is to provide longitudinal information on the experiences of youth with disabilities in their transition from secondary school to early adulthood. The NLTS was mandated by Congress in 1983. The study contains a variety of information on special education students including: social experiences, school programs, school characteristics and policies, school achievement and completion, employment characteristics, postsecondary education participation, services provided by the school and other sources, parental expectations for youth in education, employment, and independence. Data were collected from three sources: parent/guardian surveys, school records, and school program surveys. Two-stage stratified cluster sampling was used: a stratified random selection of 450 school districts and stratified random selection of 12,833 students within those districts. School districts were stratified by region, district wealth, and student enrollment. Students were stratified by age and disability category. Interviews were completed for 10,369 students for a response rate of 84%. The NLTS is a longitudinal study. Students included in the 1987 wave were retained for follow-up in 1990. Standard errors were calculated using pseudo-replication and the effective sample size estimation. The standard errors obtained under these two ways were compared using scatter plots. Estimates of effective sample size were similar to results obtained using pseudo-replication, so the more cost effective estimates of effective sample size were used. To correct for error remaining, the standard errors produced using the estimation formula were increased by a factor of 1.25. Statistical tabulations are contained in 10 volumes of almanacs and in various subject matter reports.
EVALUATION OF SURVEY	Assignment of disability category is based on the primary disability designated by the youth's school or district in the 1985-86 school year. Therefore, subgroups were defined based on how the student was classified by his or her school system. These classifications and assessments vary widely between states and school districts. Therefore, data should be interpreted as describing youth who were categorized as having a particular disability by their school or district.

SURVEY VARIABLES

Age	13-21 as of 1985-86 school year; date of birth
Sex	Male, female
Ethnicity	Black, White, Hispanic, American Indian/Alaskan Native, Asian/Pacific Islander
Family income	1986 household income
Place of residence	Urban, suburban, rural
Specific disability	Learning disabled, emotionally disturbed, speech impaired, mentally retarded, visually impaired, hard of hearing, deaf, orthopedically impaired, other health impaired, multiply handicapped, deaf/blind
Functional limitations	Self-care (dressing, feeding, getting around), functional skills (counting change, telling time, reading signs, using phone)
Family composition	Single parent, neither natural parent, other disabled children, disabled head of household
Eligibility for federal programs	Receiving: Social Security Disability Income, Social Security survivors benefits, Supplemental Security Income, Medicaid or equivalent, Aid to Families with Dependent Children, public assistance, food stamps, other benefits, no benefits

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Available by individual request from: Carolyn Estey or Kathy Valdes SRI International 333 Ravenswood Avenue Menlo Park, CA 94025 Phone: 415-859-5109 or 415-859-4974
REPORTS	Valdes, K. A., Williamson, D. C., and Wagner, M. M. (1990). The National Longitudinal Transition Study of Special Education Students. Statistical Almanac, Volume 1: Overview. Menlo Park, CA: SRI International. Wagner, M. M., D'Amico, R., Marder, C., Newman, L., & Blackorby, J. (1992). What happens next? Trends in postschool outcomes of youth with disabilities. The second comprehensive report from the National Longitudinal Transition Study of Special Education Students. Menlo Park, CA: SRI International. Wagner, M. M., Newman, L., D'Amico, R., Jay, E. D., Butler-Nalin, P., Marder, C., & Cox, R. (1991). Youth with disabilities: How are they doing? The first comprehensive report from the national Longitudinal Transition Study of Special Education Students. Menlo Park, CA: SRI International. Wine, J. S., Hayward, B. J., & Wagner, M. (1993). Vocational rehabilitation services and outcomes of transitional youth: Final Report. Research Triangle Park, NC: Research Triangle Institute.

NATIONAL POSTSECONDARY STUDENT AID STUDY (NPSAS)

AGENCY	National Center for Education Statistics U.S. Department of Education
ADDRESS	555 New Jersey Avenue, N.W. Washington, DC 20208
CONTACT	Drew Malizio
PHONE	202-219-1448
FUNDING SOURCE	National Center for Education Statistics U.S. Department of Education
FREQUENCY OF DATA COLLECTION	Every three years
DATES OF COVERAGE	1986-1987; 1989-1990; 1992-1993 academic years
DESCRIPTION OF SURVEY	The purpose of the survey is to identify students enrolled in postsecondary education and obtain information on their enrollment characteristics, financial aid status, student costs of attendance, and demographic and socioeconomic characteristics. The sample for the 1986-87 (NPSAS:87) data collection consisted of students enrolled in the Fall of 1986. The sample for 1989-90 (NPSAS:90) consisted of students enrolled throughout the 1989-90 academic year, a more accurate representation of postsecondary students. The 1989-90 NPSAS included a stratified sample of approximately 69,000 eligible students, about 47,000 of whom were undergraduates from about 1,100 institutions. The sample was selected using a three-step procedure with stratified samples and differential probabilities of selection at each level. First, postsecondary institutions were initially selected within geographical strata. Once institutions were organized by zip code and state, they were further stratified by control (public, private, not-for-profit or proprietary) and offering (less than 2 year, 2 to 3 year, 4 year non-doctoral granting, and 4 year doctoral granting). Sampling rates for students enrolled at different institutions and levels (undergraduate or other) varied, resulting in better data for policy purposes, but at a cost to statistical efficiency. For each of the students, there were up to three sources of data. First, institution registration and financial aid records were extracted. Second, a Computer Assisted Telephone Interview (CATI) designed for each student was conducted. Finally, a CATI designed for the parents or guardians of a subsample of students was conducted.
EVALUATION OF SURVEY	NPSAS:90 surveyed a representative sample of students enrolled throughout the entire 1989-90 academic year; NPSAS:87 surveyed students in the fall 1986 term. Therefore, the two datafiles are not directly comparable. However, a trend report comparing Fall 1989 enrollees with those enrolled in the Fall of 1986 is forthcoming. Disabled students attending postsecondary institutions may not be representative of disabled individuals in the general population or of other types of disabled students. The NPSAS data on disability status is self-reported. Some students may overreport or underreport their physical conditions.

SURVEY VARIABLES

Age	15 and older
Sex	Male, female
Ethnicity	White (non-Hispanic), Black (non-Hispanic), Hispanic, American Indian, Asian American
Attendance status	Full time; at least half-time; less than half-time
Housing status	School owned; off campus not with parents; with parents
Employment status	No employment; outside school period; inside school period; employed all times
Type of student aid	Grant; loan; work-study; tuition waiver; assistantship
Educational aspirations	Voc-tech, less than 2 years; voc-tech, 2 years and above; some college or AA degree; Bachelor's degree; advanced degree
Source of student aid	Federal, state, institutional, employer
Disability	Self-reported learning disability; visual handicap; hard of hearing; deafness; speech disability; orthopedic impairment; health impairment
Institution	Public; private not-for-profit; private for-profit

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	NPSAS is a restricted use data file. Users must apply for license and agree to abide by confidentiality restrictions. Initial request must be made in writing on organization letterhead. Applicants will then be sent a licensing application. Alan Moorehead Data Security Officer OERI/NCES Statistical Standards and Methodology Division U.S. Department of Education 555 New Jersey Avenue, NW, Room 408 Washington, DC 20208-5654 Phone: 202-219-1831
REPORTS	Greene, B., & Zimbler, L. (1989). Profile of handicapped students in postsecondary education, 1987: 1987 national postsecondary student aid study. Washington, DC: Office of Educational Research and Improvement, U.S. Department of Education. National Center for Education Statistics (1993). Profile of undergraduates in U.S. postsecondary education institutions:1989-90. Statistical analysis report, NCES 93-091). Washington, DC: U.S. Department of Education.

PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH MENTAL ILLNESS (PAIMI)

AGENCY	Protection and Advocacy Program Center for Mental Health Services Substance Abuse and Mental Health Services Administration U.S. Department of Health and Human Services
ADDRESS	5600 Fishers Lane Rockville, MD 20857
CONTACT	Natalie Reatig Program Chief
PHONE	301-443-3667
FUNDING SOURCE	Center for Mental Health Services
FREQUENCY OF DATA COLLECTION	Annually
DATES OF COVERAGE	Fiscal year 1992
DESCRIPTION OF SURVEY	State Protection and Advocacy for Individuals with Mental Illness (PAIMI) programs are required to provide information to the Center for Mental Health Services (CMHS), part of the Substance Abuse and Mental Health Services Administration of the Department of Health and Human Services to fulfill reporting requirements under section 105(a)(7) of P.L. 99-319, the Protection and Advocacy for Individuals with Mental Illness Act of 1986. There are 56 Protection and Advocacy (P&A) systems, one in each of the 50 states, the District of Columbia, the Virgin Islands, Puerto Rico, Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands. Forty-three of the P&A systems are private not-for-profit organizations; the remainder are located within state agencies or special departments which are independent of those providing mental health treatment or service. The law authorizes formula grant allotments to be awarded to Protection and Advocacy Systems to protect and advocate the rights of persons with developmental disabilities. The allotments are provided to pursue administrative, legal, and other appropriate remedies to protect and advocate the rights of individuals with mental illness and to investigate incidents of abuse, neglect, and rights violations.
EVALUATION OF SURVEY	Protection and Advocacy systems are independent agencies responsible for establishing their own policies, priorities, scope of activities, and data collection systems. Definition of terms used to report data may differ between states. There is great variation among the states with respect to the nature and extent of other protection and advocacy services available. These factors should be considered when comparing statistical information across individual states. Overall, the national information provides an accurate picture of what types of advocacy are taking place, which issues are being addressed, and what clients are being served.

SURVEY VARIABLES

Age	At time of contact with PAIMI program
Sex	Male, female
Ethnicity	White, African American, Asian, Native American, Pacific Islander, Hispanic origin, other
Living arrangements at time of intake	Independent; public mental health facility; community residential facility; private mental health facility; with family members or foster care; state prison or forensic unit; nursing home; municipal detention facility or jail; and public and private homeless shelter
Location	Urban (population over 50,000); rural (population under 50,000)
Type of client complaint	Abuse, neglect, denial of rights
Type of intervention strategy	Counseling/professional assistance; administrative remedies; negotiation and mediation; supervised referrals; legal remedies; other
Non-case directed services	Class action litigation; information and referral services; public education and training; systemic advocacy; and legislative advocacy
Services to special populations	Children and adolescents; penal system; minority populations

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Not available
REPORTS	Center for Mental Health Services (1992). Fiscal Year 1992 Report on Activities under Public Law 99-319, the Protection and Advocacy for Individuals with Mental Illness Act of 1986. Rockville, MD: U.S. Department of Health and Human Services.

REHABILITATION SERVICES ADMINISTRATION CASE SERVICE REPORT (RSA 300-911)

AGENCY	Rehabilitation Services Administration U.S. Department of Education
ADDRESS	Switzer Building 330 C Street, S.W. Washington, DC 20202
CONTACT	Larry Mars
PHONE	202-205-9404
FUNDING SOURCE	Rehabilitation Services Administration
FREQUENCY OF DATA COLLECTION	Annually
DATES OF COVERAGE	Fiscal year 1991
DESCRIPTION OF SURVEY	The state-federal program of vocational rehabilitation (VR) is authorized by the Rehabilitation Act of 1973, as amended. The purpose of the program is to provide individualized rehabilitation services to disabled persons to help them attain, maintain, or regain employment. The RSA-911 reporting system files contain personal economic, program-related and outcome data on each of 600,000 disabled persons whose cases are closed each year by over 80 state vocational rehabilitation agencies. Approximately 200,000 clients are successful closures where the client is fully rehabilitated and placed in employment. In fiscal year 1991, 68,938 applicants were under age 21.
EVALUATION OF SURVEY	The database contains detailed information on closed cases, ranging from successfully rehabilitated and placed in employment, to cases closed with no services provided. The most detailed information is available for successfully rehabilitated clients.

SURVEY VARIABLES

Age	Date of birth
Sex	Male, female
Ethnicity	White, Black, American Indian/Alaska Native, Asian/Pacific Islander, Hispanic
Marital status	Married, widowed, divorced, separated, never married
Education	Highest grade completed
Location	State, District of Columbia, U.S. territories and possessions
Major and secondary disabling condition	Visual impairment, hearing impairment, orthopedic impairment, absence of limbs, mental illness, substance abuse, mental retardation, respiratory disorders, digestive disorders, heart/circulatory, genitourinary, learning disabilities, other
Work status	At application and at closure
Weekly earnings	At application and at closure
Hours worked	At application and at closure

Services provided	Diagnosis, restoration, college training, vocational training, adjustment training, on-the-job training, miscellaneous training, counseling, job referral, placement, transportation, maintenance
Service source	Educational institution, vocational school, hospital, health organization, rehabilitation facility, welfare agency, other public agency, other private agency, private individuals
Referral source	Educational institution, hospital, health organization, welfare agency, other public organization, other private organization, self-referral, physician, other individual
Primary source of support	Client income, family/friends, private relief agency, federal public assistance, non-federal public assistance, public institution, workers' compensation, SSDI

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Data available on disk for legitimate research purposes upon written request. David Ziskind, Chief Basic State Grants Branch Rehabilitation Services Administration U.S. Department of Education 330 C Street, S.W. Washington, DC 20202 Phone: 202-205-5474

STATE REPORTS TO THE OFFICE OF SPECIAL EDUCATION PROGRAMS

AGENCY	Office of Special Education Programs U.S. Office of Special Education and Rehabilitative Services U.S. Department of Education
ADDRESS	Switzer Building 330 C Street, S.W. Washington, DC 20202
CONTACT	Scott Brown
PHONE	202-205-8117
FUNDING SOURCE	Office of Special Education Programs
FREQUENCY OF DATA COLLECTION	Annual
DATES OF COVERAGE	1976-77 through 1991-92 school year
DESCRIPTION OF SURVEY	States annually report to the Office of Special Education Programs in the U.S. Department of Education. The information is required under the Individuals with Disabilities Education Act (IDEA) in order to describe the progress being made in implementing IDEA. The IDEA child count is recorded on December 1. Local school districts are responsible for disseminating and collecting all child count information from educational agencies in their local districts. Local School districts submit program level summary forms to the State Department of Education. State Departments of Education report the aggregated information using standard reporting forms provided by the U.S. Department of Education. The IDEA reports include number of children receiving special education and related services, number of children with disabilities receiving special education in various settings, exiting status of special education students, and the number of school personnel available and needed to provide such services. The most recent child count information is for school year 1991-92. Information on setting, exiting status, and personnel is for school year 1990-91. During the 1991-92 school year, 4,994,169 children and youth from birth through age 21 were served under Part B of IDEA and Chapter 1 of the Elementary and Secondary Education Act (ESEA), State Operated Programs (SOP).
EVALUATION OF SURVEY	The state reports provide aggregate data on children receiving special education services. However, no individual case data are available.

SURVEY VARIABLES

Age	Date of birth; includes birth through age 21
Disability	Specific learning disability, speech or language impairment, mental retardation serious emotional disturbance, hearing impairment, multiple disability, orthopedic impairment, other health impairment, visual impairment, and deaf/blindness
Educational environment	Regular class, resource room, separate class, public separate school facility, private separate school facility, public residential facility, private residential facility, correctional facility, and homebound/hospital environment
Location	States, District of Columbia, Puerto Rico, Virgin Islands, Bureau of Indian Affairs, and Pacific Territories
Teachers	Number of special education teachers employed and number needed to serve children with disabilities
Personnel other than teachers	Number of special education personnel other than teachers employed and number needed to serve children with disabilities: psychologists, school social workers, occupational therapists, audiologists, paraprofessionals, vocational education teachers, work-study coordinators, physical education coordinators, recreational therapists, diagnostic staff, supervisors, physical therapists, counselors, SEA supervisors, other non-instructional staff (e.g., health services, food services, maintenance, transportation), and non-professional staff
Basis of exit	Graduation with diploma, graduation with certificate, dropped out, reached maximum age for which services are available, and unknown
Anticipated services needed by exiting children age 14 and older	Counseling, transportation, technological aids, interpreter services, reader services, physical/mental restoration, family services, independent living, maintenance, residential services

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	The data file contains only aggregate data that are published in the annual report to Congress. There are no individual record data. Scott Brown Office of Special Education Programs U.S. Office of Special Education and Rehabilitative Services U.S. Department of Education 330 C Street, S.W. Washington, DC 20202 Phone: 202-205-8117
REPORTS	Office of Special Education Programs (1993). To assure the free appropriate public education of all children with disabilities: Fifteenth annual report to Congress on the implementation of the Individuals with Disabilities Education Act. Washington, DC: U.S. Department of Education.

STUDY OF PROGRAMS OF INSTRUCTION FOR HANDICAPPED CHILDREN AND YOUTH IN DAY AND RESIDENTIAL FACILITIES

AGENCY	Office of Special Education Programs U.S. Department of Education
ADDRESS	Switzer Building 330 C Street, S.W. Washington, DC 20202
CONTACT	Lou Danielson
PHONE	202-205-8119
FUNDING SOURCE	Office of Special Education Programs
DATES OF COVERAGE	Survey conducted in fall of 1988, covering 1987-88 school year. Case study site visits were conducted between June and October of 1987.
DESCRIPTION OF SURVEY	The Study of Programs of Instruction for Handicapped Children and Youth in Day and Residential Facilities was a Congressionally mandated study designed to study day and residential facilities which primarily or exclusively serve children and youth with disabilities. The study had three components: (1) the Survey of Separate Facilities; (2) Survey of State Divisions of Special Education; and (3) State-level case studies of eight state education agencies (SEAs) in California, Connecticut, Florida, Illinois, Louisiana, New Jersey, Ohio, and South Carolina, and facility-level case studies conducted at 24 separate facilities, three in each of the eight case study states. The Survey of Separate Facilities sampled 2,580 facilities identified as providing special education in a setting physically separate from the educational service provided to nondisabled students. Data were collected from 1,941 facilities for a response rate of 75%. Weights were formulated to account for differences across facilities in sampling and response rates. The Survey of State Divisions of Special Education obtained data from 49 states, (Hawaii did not respond), and from the District of Columbia. This survey was designed to study the impact of state procedures on separate facilities. Case studies were conducted to examine the link between SEAs and separate facilities. The case studies were designed to provide detailed information on state procedures to improve instruction for disabled children in separate facilities and on facility responses to SEA procedures.
EVALUATION OF SURVEY	The study is the first source of comprehensive national data on programs, services, students, and staff at separate facilities serving disabled children. A limitation was that facilities primarily serving students with mental retardation or serious emotional disturbance dominated. The number of facilities serving other disability groups was relatively small. Therefore, reliable estimates of their number and activities cannot be provided. For this reason, it is difficult to interpret findings on separate facilities that serve students with disabilities other than the two largest groups. Also, the small number of case studies are not statistically representative of all states or separate facilities. No data were collected at the individual student level.

SURVEY VARIABLES

Age	Date of birth; 0 - 21 year of age
Type of facility	Residential separate facility: a separate facility at which at least some handicapped persons reside and at which at least some students ages 0 to 22 receive educational services on the grounds of the facility during the usual school day Separate day school or facility: a separate facility at which no handicapped persons reside and at which students ages 0 to 22 receive educational services during the usual school day
Primary disability	Learning disability; mild/moderate mental retardation; severe/profound mental retardation; emotional disturbance; hearing impairment; visual impairment; orthopedic or physical impairment; health impairment; autism; speech or language impairment; multiple handicap; deaf-blind; and non-categorical
Operating agency	Public: State education agency, local education agency, regional agency, consortium of school districts, intermediate education agency Private: Private for profit corporation; religious organization; other
Student movement	First admission, readmission, discharges
Services to exiting students	Arranging transfer of records to new school; visiting new placement with an exiting student; training in skills specifically required in new placement; involving parents in planning and preparation for transfer to new placement; follow-up to monitor success of new placement; joint planning with the local education agency (LEA) for transition; providing back-up or additional services after new placement; providing guidance and vocational counseling to exiting students; provide job placement services; and other
Non-instructional activities	Social activities; dance, music, drama; organized physical exercise; field trips; competitive sports; special interest clubs; and other off-campus events
Staff	Administrative; classroom instructional staff; support and related services staff; operations and transportation; direct residential care staff; and volunteers
Costs	Annual operating budget; educational costs; and cost per student per day

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	For further information contact: Lou Danielson Office of Special Education Programs U.S. Department of Education 330 C Street, S.W. Washington, DC 20202 Phone: 202-205-8119
REPORTS	Stephens, S. A., Lakin, K. C., Brauen, M., & O'Reilly, F. (1990). The study of programs of instruction for handicapped children and youth in day and residential facilities. Volumes I-V. Washington, DC: Office of Special Education Programs, U.S. Department of Education.

SURVEY ON DEAF AND HARD OF HEARING STUDENTS IN POSTSECONDARY EDUCATION

AGENCY	National Center for Education Statistics Office of Educational Research and Improvement U.S. Department of Education
ADDRESS	555 New Jersey Avenue, N.W. Washington, DC
CONTACT	Bernie Greene
PHONE	202-219-1366
FUNDING SOURCE	Office of Special Education and Rehabilitative Services
DATES OF COVERAGE	The 1989-90, 1990-91, 1991--92, and 1992-93 academic years, reported by the institution in spring 1993.
DESCRIPTION OF SURVEY	The Survey was requested by the Office of Special Education and Rehabilitative Services of the U.S. Department of Education to obtain information from postsecondary education institutions about several issues: the range of postsecondary institutions in which deaf and hard of hearing students enroll, the number of deaf and hard of hearing students enrolled at these institutions, and the support services provided to these students by the postsecondary institutions. The survey was conducted in spring 1993 by the National Center for Education Statistics using the Postsecondary Education Quick Information System (PEQIS). PEQIS is designed to quickly collect limited amount of policy-relevant information from a previously recruited nationally representative stratified sample of postsecondary institutions. The survey was mailed to the PEQIS survey coordinators at 1,036 two-year and four-year postsecondary education institutions. Coordinators were told that the survey was designed to be completed by the person at the institution who had the most information about deaf and hard of hearing students. Completed questionnaires were received from 982 of the 1,025 eligible institutions, for an unweighted survey response rate of 96%. Data were adjusted for questionnaire nonresponse and weighted to provide national estimates.
EVALUATION OF SURVEY	Information about deaf and hard of hearing students was collected about only those who had identified themselves to the institution as deaf or hard of hearing. Students who identify themselves to the institutions as deaf or hard of hearing are a subset of all deaf and hard of hearing students because some deaf and hard of hearing students may choose not to identify themselves to their institutions. The information presented does not include Gallaudet University or the National Technical Institute for the Deaf, because the intent of the survey was to obtain information about deaf and hard of hearing students enrolled at institutions other than these two federally funded national programs for persons who are deaf.

SURVEY VARIABLES

Support services	Sign language interpreters/transliterators; oral interpreters/transliterators; classroom notetakers; tutors to assist with ongoing coursework; assistive listening devices; other support services
Reason for not being able to provide services	Not enough qualified personnel; qualified personnel take better jobs outside the institution; necessary equipment is not available; money to provide the service is not available; service requested was not considered reasonable or necessary for the institution to provide
Hearing level	Deaf; hard of hearing; deaf or hard of hearing (institution does not distinguish between deaf and hard of hearing)
Point of contact for support services	Office devoted entirely to services for students with disabilities; coordinator devoted entirely to services for students with disabilities, but located within another office; person or office on campus responsible for services to students with disabilities, in addition to other duties; person or office on campus provides these services when the need arises; other primary point of contact
Level of institution	2-year; 4-year
Control of institution	Public; private
Region	Northeast; Southeast; Central; West
Size of institution	Fewer than 3,000 students (small); 3,000 to 9,999 students (medium); and 10,000 or more students (large)

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Available upon written request to:
REPORTS	Lewis, L., & Farris, E. (1994). Deaf and hard of hearing students in postsecondary education: Statistical analysis report (NCES 94-394). Washington, DC: National Center for Education Statistics, U.S. Department of Education.

SURVEY OF INCOME AND PROGRAM PARTICIPATION (SIPP)

AGENCY	U.S. Bureau of the Census Housing and Household Economic Statistics Division
ADDRESS	Washington, DC 20233
CONTACT	John M. McNeil
PHONE	301-763-8300
FUNDING SOURCE	Bureau of the Census
FREQUENCY OF DATA COLLECTION	Subsample rotation groups are interviewed at 4-month intervals over two and a half years.
DATES OF COVERAGE	1990 panel, wave 6 (last 3 months of 1991); 1991 panel, wave 3 (first month of 1992)
DESCRIPTION OF SURVEY	The Survey of Income and Program Participation (SIPP) is a panel survey of the economic conditions of people in the United States. It is designed to provide detailed information about income distribution and about federal and state income transfer and service programs. It also provides information for respondents 15 and older about limiting conditions. Disability data for children ages 0 through 14 are obtained from their parents.
EVALUATION OF SURVEY	The severe space limitations that apply to the decennial census questionnaire do not apply to the questionnaire used in the SIPP. The ability to gather fairly detailed information on a range of subjects is a strength of the SIPP program. A limitation of the survey is the relatively small sample size. The data set used as the basis of the report on disability was obtained by combining data from the sixth wave of the 1990 panel with data from the third wave of the 1991 panel. The combined sample size was approximately 30,000 households. SIPP contains information on economic and social variables of persons with disabilities that are not usually included in health surveys that ask about disability.

SURVEY VARIABLES

Age	Current age
Sex	Male, female
Ethnicity	White, not of Hispanic origin; of Hispanic origin; Black; American Indian; Asian.

Limitations	Children under age 6: Any limitations in the usual kind of activities done by most children their age, because of a physical, learning, or mental health condition. Whether children had received therapy or diagnostic services designed to meet their developmental needs Children between the ages of 6 and 21: Any limitations in their ability to do regular school work because of a physical, learning, or mental health condition. Have ever received or are currently receiving any special education services. Children between the ages of 3 and 14: Long lasting condition that limits ability to walk, run, or use stairs.
Health conditions	Asthma; autism; blindness or vision problems; cancer; cerebral palsy; deafness or serious trouble hearing; diabetes; drug or alcohol problem or disorder; epilepsy or seizure disorder; hay fever or other respiratory allergies; head or spinal cord injury; heart trouble; impairment or deformity of back, side, foot, or leg; impairment or deformity of finger, hand, or arm; learning disability; mental or emotional problem or disorder; mental retardation, missing legs, feet, toes, arms, hands, or fingers; paralysis of any kind; speech problems; tonsillitis or repeated ear infections, other

AVAILABILITY OF DATA

TAPES AND DOCUMENTATION	Customer Services U.S. Bureau of the Census Washington, DC 20233 Phone: 301-763-4100 FAX: 301-763-4794
REPORTS	McNeil, J. M. (1993). <u>Americans with disabilities: 1991-92</u>. Current Population Reports, Household Economic Studies P70-33. Washington, DC: U.S. Bureau of the Census. McNeil, J. M. (1993, June). Census Bureau data on persons with disabilities: New results and old questions about validity and reliability. Paper presented at the meeting of the Society for Disability Studies, Seattle, WA. LaPlante, M. P. (1992). Using the Survey of Income and Program Participation in disability research and policy. <u>Journal of Economic and Social Measurement, 18</u>, 125-154.

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Baker, P. C., Keck, C. K., Mott, F. L., & Quinlan, S. V. (1993). NLSY child handbook, revised ed.: A guide to the 1986-1990 National Longitudinal Survey of Youth, Child Data. Columbus, OH: Center for Human Resource Research, The Ohio State University.

Baumeister, A. A., Kupstas, F. D., & Woodley-Zanthos, P. (1993). The new morbidity: Recommendations for action and an updated guide to state planning for the prevention of mental retardation and related disabilities associated with socioeconomic conditions. Washington, DC: President's Committee on Mental Retardation.

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Center for Assessment and Demographic Studies (1993). Annual survey of deaf and hard-of-hearing children and youth, regional and national summary: 1992-93. Unpublished tabulations. Washington, DC: Gallaudet University.

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Disability Statistics Program (April 1992). People with disabilities in basic life activities in the U.S. Disability Statistics Abstract 3. Washington, DC: National Institute on Disability and Rehabilitation Research.

Disability Statistics Program (December 1991). People with activity limitations in the U.S. Disability Statistics Abstracts 2. Washington, DC: National Institute on Disability and Rehabilitation Research.

Edmonds, L. D., & James, L. M. (1993). Temporal trends in the birth prevalence of selected congenital malformations in the Birth Defects Monitoring Program/Commission on Professional and Hospital Activities, 1979-1989. Teratology, 48, 647-649.

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Haber, L. D., (1990). Issues in the definition of disability and the use of disability survey data. In D. B. Levine, M. Zitter, & L. Ingram (Eds.), Disability statistics: An assessment, (pp. 35-51). Washington, DC: National Academy Press.

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Lakin, K. C., Blake, E. M., Prouty, R. W., Mangan, T., & Bruininks, R. H. (1993). Residential services for persons with developmental disabilities: Status and trends through 1991. Report #38. Minneapolis, MN: Center on Residential Services and Community Living, University of Minnesota.

LaPlante, M. P. (1992). Using the Survey of Income and Program Participation in disability research and policy. Journal of Economic and Social Measurement, 18, 125-154.

LaPlante, M. P. (1991a). The demographics of disability. The Milbank Quarterly, 68, Supplements 1/2, 55-77.

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