Chartbook on Mental Health and Disability in the United States

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Foreword

The establishment of the President's New Freedom Commission on Mental Health marks an important step in improving the lives of people with disabilities due to mental disorders. The wide prevalence of mental disorders, and the need for improved services and resources, is addressed in the Commission's report "Achieving the Promise: Transforming Mental Health Care in America" (New Freedom Commission, 2003). Together with the 1999 Surgeon General's Report, the Commission's report makes a compelling case for increased research to enhance our understanding of mental disorders. The National Institute on Disability and Rehabilitation Research, U.S. Department of Education, is concerned with the disabling effects of mental disorders, and supports research leading to improved choices, services and outcomes.

This InfoUse Chartbook is one in a series of NIDRR-supported statistical chartbooks intended for a broad public audience. Drawing from national surveys and statistical research, this Chartbook presents information on the prevalence of mental disorders, and the extent to which mental disorders contribute to reduced participation in major life activities such as school and work. While existing information can be used to describe the issues and to engage in planning for improved services, the available surveys have serious limitations. Surveys use different definitions and terminology, and some key information is available only in older surveys or data sources. As we move toward the transformation of mental health care, it is important to continue to build our data sources, knowledge, and understanding.

Steven Tingus, Director
National Institute on Disability and Rehabilitation Research

Acknowledgments

The *Chartbook on Mental Health and Disability in the United States* relies on published data from many federal agencies and organizations. We appreciate all of the people and agencies responsible for collecting, maintaining, and analyzing these data.

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Preface

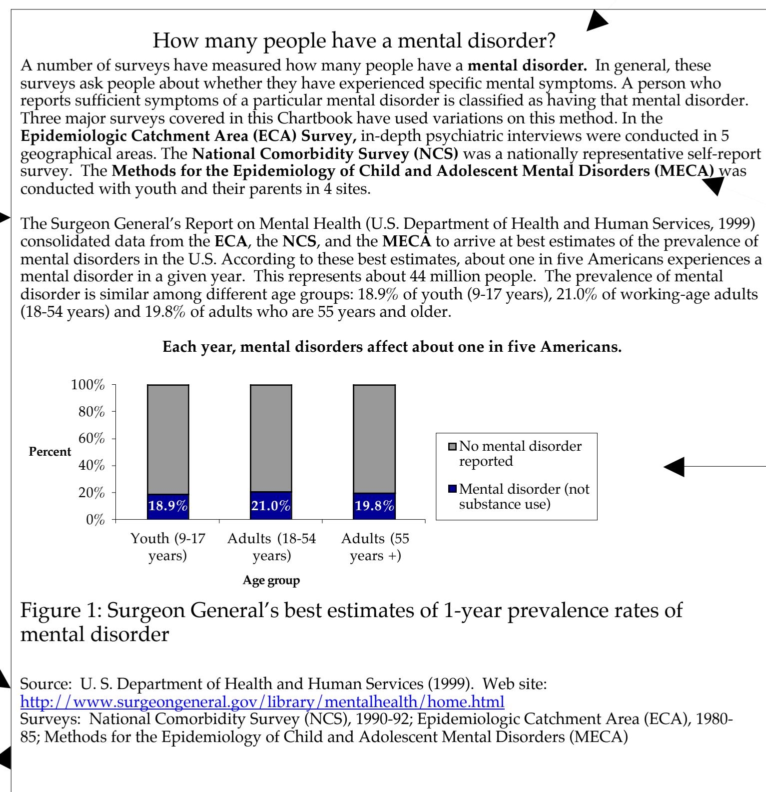
The **Chartbook on Mental Health and Disability in the United States** is a reference on disability and mental health in the United States, created for both non-technical and technical audiences. The book is a resource for agencies, employers, organizations, policymakers, researchers and others concerned with the relationship between mental health and disability.

Each section addresses an aspect of mental health and disability. Each page within the section contains a topic question, explanatory text on the topic and an explanatory graphic or table that provides data in an easy to read form. The figure title gives the name of the graphic. The source of the information and the survey used to collect the data appear at the bottom of the page. The key surveys, shown in **boldface** when mentioned in the text, have a technical summary that is located in the Appendix. In the text, key terms are also shown in **boldface** and are defined in the Glossary.

Topic Question

Explanatory text, using data from original source

Boldface terms are defined in Glossary or Appendix



How many people have a mental disorder?

A number of surveys have measured how many people have a **mental disorder.** In general, these surveys ask people about whether they have experienced specific mental symptoms. A person who reports sufficient symptoms of a particular mental disorder is classified as having that mental disorder. Three major surveys covered in this Chartbook have used variations on this method. In the **Epidemiologic Catchment Area (ECA) Survey,** in-depth psychiatric interviews were conducted in 5 geographical areas. The **National Comorbidity Survey (NCS)** was a nationally representative self-report survey. The **Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA)** was conducted with youth and their parents in 4 sites.

The Surgeon General's Report on Mental Health (U.S. Department of Health and Human Services, 1999) consolidated data from the **ECA**, the **NCS**, and the **MECA** to arrive at best estimates of the prevalence of mental disorders in the U.S. According to these best estimates, about one in five Americans experiences a mental disorder in a given year. This represents about 44 million people. The prevalence of mental disorder is similar among different age groups: 18.9% of youth (9-17 years), 21.0% of working-age adults (18-54 years) and 19.8% of adults who are 55 years and older.

Each year, mental disorders affect about one in five Americans.

Figure 1: Surgeon General's best estimates of 1-year prevalence rates of mental disorder

Source: U. S. Department of Health and Human Services (1999). Web site: http://www.surgeongeneral.gov/library/mentalhealth/home.html
Surveys: National Comorbidity Survey (NCS), 1990-92; Epidemiologic Catchment Area (ECA), 1980-85; Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA)

Explanatory graphic, created with data from the published source

Source of analysis by author name and year; complete citations in bibliography

Survey from which the data were derived; explanation in Appendix.

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Introduction

Mental disorders affect about one fifth of the United States population in a given year. If people with mental disorders are to participate actively and productively in our communities, workplaces and schools, resources must be expanded and services improved. Many researchers and professionals have contributed to our understanding of mental disorders and to improved treatment, medication, services and benefits. Much, however, remains to be accomplished.

This **Chartbook on Mental Health and Disability** provides easy-to-understand statistics about people who have mental disorders and people who have disabilities caused by mental disorders. Designed for use by policymakers, the press, and the public, the Chartbook summarizes important information from national surveys and from available research. This is a resource useful to people in the mental health field and people in the disability community, presenting research findings to create a bridge between those two perspectives.

In the area of mental health and disability, it is particularly difficult to find accurate and consistent language that is understood and accepted by both mental health and disability audiences. Following the lead of the Surgeon General's 1999 report, we have chosen to use the general term **mental disorder** to describe "health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning" (U.S. Department of Health and Human Services, 1999, p. vii). The studies and surveys on which this Chartbook is based have used other terms that are roughly synonymous with mental disorder, including **mental condition**, **mental illness,** and **psychiatric disorder.** These terms are defined in the text and in the glossary.

Not all people who have a mental disorder have a disability. This Chartbook is primarily about people who experience limitation in important life activities as a result of having a mental disorder -- a **disability due to a mental disorder**. Researchers have used the related terms **mental health disability**, **severe mental illness**, **serious mental illness**, and **mental disability** that are roughly equivalent to the term **disability due to a mental disorder**. On the pages that present information from particular studies and surveys, we use the terminology established by that study or survey finding.

In general we have not included people with mental retardation or learning disabilities in the categories of **mental disorders** and **disabilities due to mental disorders**. Occasionally, data sources do include those groups in the statistics. On those particular pages, we have noted when those groups are included.

Section One includes information on how many people have mental disorders and disabilities due to mental disorders. The concept of disability includes not only the diagnosis of a mental disorder but also limitations in basic activities due to the disorder.

Section Two provides additional information on disability due to mental disorders among adults. Adults with mental disorders may face limitations in their day-to-day activities, including work. The employment rate for people with mental disorders is much lower than the national employment rate, and is especially low for people with disabilities due to mental disorders.

Section Three includes estimates of how many children have disabilities due to mental disorders. Almost ten percent of the children in the **special education** system are identified as having **emotional disturbance.** Students with emotional disturbance have higher dropout rates than other students, and are less likely to successfully complete high school.

Section Four provides information on resources, benefits, and services designed to address the needs of people with disabilities due to mental disorders, and to reduce or eliminate barriers to their full participation. The need for services and resources is apparent in increased demand for Social Security support, as well as the use of services provided by Vocational Rehabilitation and Independent Living Centers. The service gap is also reflected in the numbers of people who are homeless, the numbers without access to needed care and treatment, and the extent to which both juveniles and adults receive mental health services through prisons and jails. The shortfall in appropriate treatment and services results in lost productivity, lost lifetime earnings, and cost of care for people with disabilities due to mental disorders.

Section Five addresses gaps in available information and services, and the need for better survey information.

Section 1: Mental health and disability
Definitions and prevalence

Many studies have been conducted to determine how many people in the United States have mental disorders and disabilities due to a mental disorder. Estimates differ, depending on how the disorders and disabilities are defined and measured, and depending on which populations are included in the surveys. This section provides information on the prevalence of mental disorders, and presents results from several sources on the extent to which mental disorders contribute to disability. Approximately 20% of people in the United States experience **mental disorders** in a given year. Various measures of **disability due to mental disorders**, such as **mental health disability, mental disability, severe mental illness,** and **serious mental illness,** provide an understanding of the extent to which mental disorders contribute to limitations in daily activities and functioning of 3 to 7% of the population.

Topic Questions:

How many people have a mental disorder?

How many people have a mental health disability?

What types of disabilities are experienced by people with mental disorders?

How many people have a mental disability and what are their conditions and symptoms?

What percentage of the adult population has severe mental illness and what disorders do they have?

How many people have a serious mental illness?

How many people have a mental disorder?

A number of surveys have measured how many people have a **mental disorder.** In general, these surveys ask people about whether they have experienced specific mental symptoms. A person who reports sufficient symptoms of a particular mental disorder is classified as having that mental disorder. Three major surveys covered in this Chartbook have used variations on this method. In the **Epidemiologic Catchment Area Survey (ECA),** in-depth psychiatric interviews were conducted in 5 geographical areas. The **National Comorbidity Survey (NCS)** was a nationally representative self-report survey. The **Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA)** was conducted with youth and their parents in 4 sites.

The Surgeon General's Report on Mental Health (U.S. Department of Health and Human Services, 1999) consolidated data from the ECA, the NCS, and the MECA to arrive at best estimates of the prevalence of mental disorders in the U.S. According to these best estimates, about one in five Americans experiences a mental disorder in a given year. This represents about 44 million people. The prevalence of mental disorder is similar among different age groups: 18.9% of youth (9-17 years), 21.0% of working-age adults (18-54 years) and 19.8% of adults who are 55 years and older.

Each year, mental disorders affect about one in five Americans.

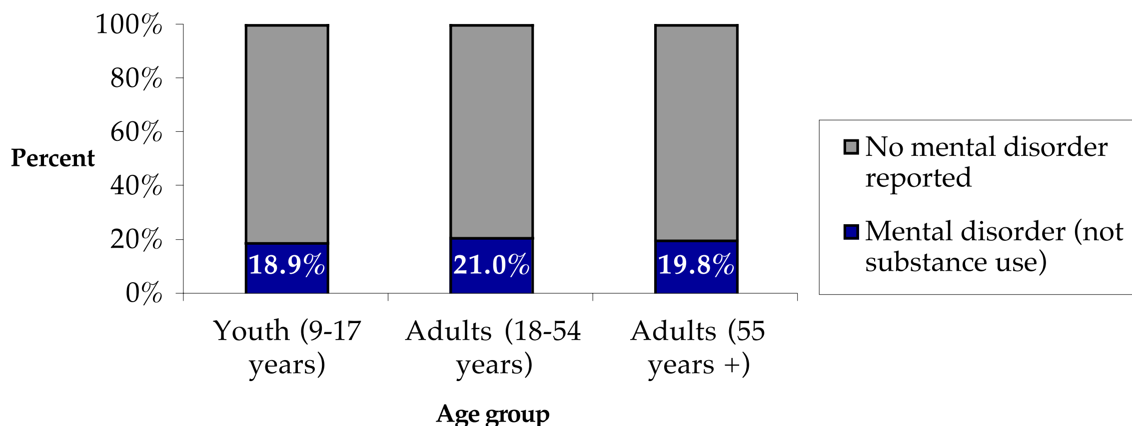


Figure 1: Surgeon General's best estimates of 1-year prevalence rates of mental disorder

Source: U. S. Department of Health and Human Services (1999). Web site: http://www.surgeongeneral.gov/library/mentalhealth/home.html
Surveys: National Comorbidity Survey (NCS), 1990-92; Epidemiologic Catchment Area (ECA), 1980-85; Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA), 1991-92

How many people have a mental health disability?

Mental health disability is a term that describes people with **disabilities due to mental disorders**. People with a mental health disability report certain mental disorders and/or symptoms that limit their activities. The disorders include schizophrenia, paranoid or delusional disorder, bipolar disorder, major depression, personality disorders, Alzheimer's, substance abuse disorders or other disorders, but not learning disability or mental retardation. The symptoms include being frequently depressed or anxious, having serious difficulty coping with day-to-day stresses, and others. Limited in activity means that they indicated that the disorders and/or symptoms seriously interfere with their ability to work or attend school, or manage day-to-day activities.

Using this measure, 3.5% of the adult U.S. civilian **non-institutionalized** population is estimated to have a mental health disability (6.7 million people). In comparison, 15.4% of the population is estimated to have a physical health disability without a co-occurring mental health disability (29.3 million).

About 6.7 million adults (3.5% of the population) have a mental health disability.

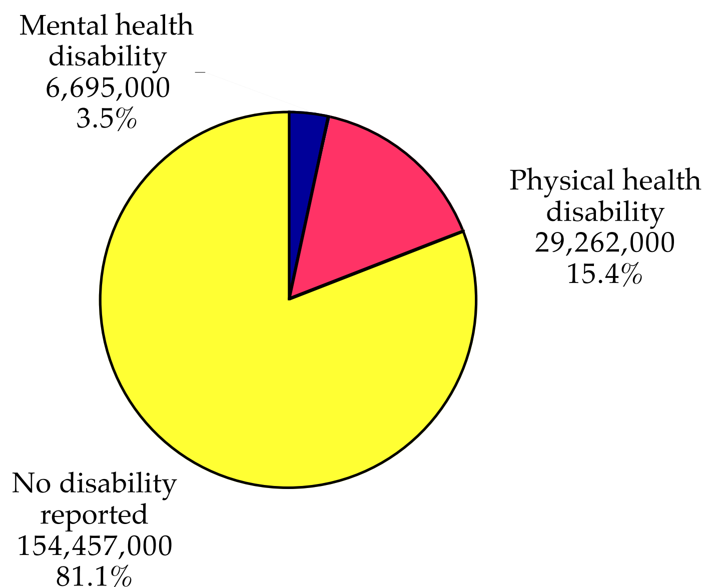


Figure 2: Number and percentage of U.S. civilian non-institutionalized population, 18 years and older, with mental health disability, physical health disability, and no reported disability

Source: LaPlante (2002)
Survey: NHIS, 1994-95, NHIS-D, 1994-95

What types of disabilities are experienced by people with mental disorders?

The **National Health Interview Survey on Disability** (NHIS-D, 1994-95) estimates the extent of disability associated with mental disorder, using four different definitions of disability. The first, **functional disability,** includes any serious symptoms of **mental illness** that severely interfered with life for the past year (as well as physical and sensory limitations, use of **personal assistance** and other criteria.) The second, **work disability**, is defined as a limitation in or inability to work as a result of physical, mental or emotional health conditions. **Perceived disability** refers to whether people consider themselves to have a disability or are considered by others to have one. Finally, **disability program recipient** includes anyone covered by **Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), special education** or related services and/or disability pensions.

"Any disability" is an unduplicated count of people in the four other categories; by this measure, more than two-thirds (69.8%) of people with mental disorders have a disability. Using the concept of functional disability, 63.8% of people with mental disorders have a disability, while about one-third of people with mental disorders have a perceived disability (35.8%) or a work disability (30.0%). Less than 20% of those with mental disorders are disability program recipients (18.3%).

More than two-thirds of people with mental disorders have a disability.

	People with mental disorders (23.5 million)		
Disability status	**# in millions**	**% of U.S. population**	**% of people with mental disorders**
Any disability (1 or more of 4)	16.4	6.3%	69.8%
1) Functional disability	15.0	5.8%	63.8%
2) Work disability	6.1	2.3%	30.0%
3) Perceived disability	8.4	3.2%	35.8%
4) Disability program recipient	4.3	1.7%	18.3%

Figure 3: Prevalence of disability among those with mental disorders

Sources: Adler (1996); Kennedy, et al. (1997)
Survey: NHIS-D, 1994-95

How many people have a mental disability and what are their conditions and symptoms?

People who answered that they had specific mental conditions and symptoms were classified as having a **mental disability** in an analysis of the **Survey of Income and Program Participation (SIPP)**. In 1997, 14.3 million people age 15 and over (6.9%) had a mental disability. An estimated 3.9 million people had only a mental disability, 727,000 people had both mental and communication disabilities, 5.3 million people had both mental and physical disabilities, and 4.3 million people had mental, physical, and communication disabilities.

Furthermore, 8.1 million people (3.9% of the population) reported one or more mental conditions (learning disability; mental retardation; Alzheimer's, senility, or dementia; and other mental/emotional condition). Another 6.9 million (3.3%) reported one or more mental symptoms that seriously interfered with their ability to manage day-to-day activities (frequently anxious or depressed; trouble coping with stress; trouble concentrating; trouble getting along with others). Finally, 4.6 million (2.2%) reported difficulty keeping track of money and bills.

Over 14 million people age 15 and over have a mental disability associated with specific conditions and symptoms.

	People age 15 years and older	
	Number	**Percent**
With a mental disability	**14,267,000**	**6.9%**
With 1 or more selected conditions	**8,144,000**	**3.9%**
A learning disability	3,451,000	1.7%
Mental retardation	1,366,000	0.7%
Alzheimers, senility or dementia	1,873,000	0.9%
Other mental/emotional condition	3,418,000	1.6%
With 1 or more selected symptoms that seriously interfered with everyday activities	**6,862,000**	**3.3%**
Frequently depressed or anxious	5,615,000	2.7%
Trouble getting along with others	1,816,000	0.9%
Trouble concentrating	3,753,000	1.8%
Trouble coping with stress	4,659,000	2.2%
Had difficulty keeping track of money/bills	**4,636,000**	**2.2%**

Figure 4: Percentage of people with mental conditions, with symptoms that interfere with everyday activities, and with difficulty keeping track of bills

Source: McNeil, (2001)
Survey: SIPP, 1997

What percentage of the adult population has severe mental illness, and what disorders do they have?

The National Institute of Mental Health analyzed the **Epidemiologic Catchment Area (ECA)** data to determine the percentage of adults who have **severe mental illness**. (In some studies the term "severe and persistent mental illness" is used as an equivalent.) This definition is based on the specific psychiatric diagnoses as well as the duration and severity of the symptoms. People who, during the prior year, had disorders that are usually accompanied by psychotic symptoms (schizophrenia, and severe forms of bipolar disorder) were included in the severe mental illness category. In addition, people with other diagnoses (major depression, panic disorder, and obsessive-compulsive disorder) were included in the severe mental illness category only if there was evidence that the disorder had been disabling in the past year. Using this definition, about 2.8% of the U.S. adult population are estimated to have a severe mental illness. Schizophrenia (1.5%) major depression (1.1%), and bipolar disorder or manic depressive illness (1.0%) were the most common disorders among people with severe mental illness.

About 2.8% of the U.S. adult population have severe mental illness, most commonly schizophrenia, major depression, or bipolar disorder.

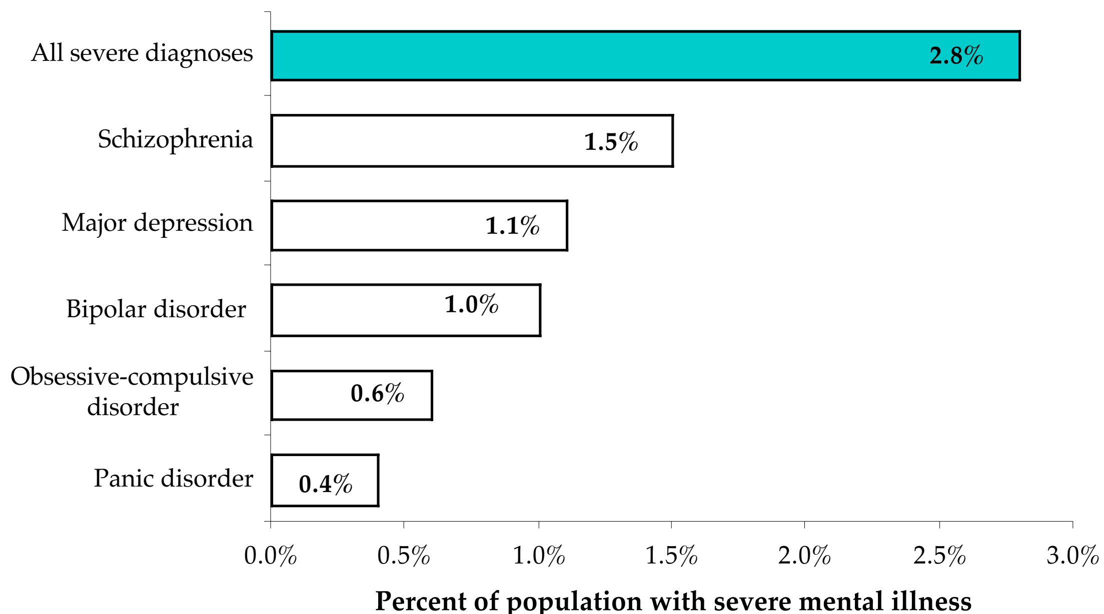


Figure 5: Percentage of adults with disorders included in the category of severe mental illness, by disorder

Source: National Advisory Mental Health Council (1993)
Survey: Epidemiologic Catchment Area (ECA), 1980-85

How many people have a serious mental illness?

Serious mental illness is a broader category of mental disorders that includes **severe mental illness**. The term serious mental illness is used to distinguish mental disorders that cause disability from mental disorders that do not result in disability. Under the Alcohol, Drug Abuse, and Mental Health Administration (ADAMHA) Reorganization Act of 1992, serious mental illness was defined as having any **DSM** mental disorder that leads to "substantial interference with one or more life activities." Specifically, serious mental illness included people whose disorder substantially interfered with their vocational capacity, created serious interpersonal difficulties, or was associated with a suicide plan or attempt.

It is estimated that about 10 million people (5.4% of the non-institutionalized civilian U.S. population 18 years and older) have a serious mental illness. Adding **synthetic estimates** for people in correctional institutions, nursing homes and other institutions, military personnel and homeless people, brings the overall estimate to 12.2 million people with serious mental illness.

Over 12 million adults in the U.S. have a serious mental illness.

	With serious mental illness	No serious mental illness	Total
Non-institutionalized civilian population	10,000,000	175,000,000	185,000,000
Synthetic estimates of population in institutions and homeless	2,200,000	2,800,000	5,000,000
Estimates of total population	12,200,000	177,800,000	190,000,000

Figure 6: Estimates of U.S. adults 18 years and over, with serious mental illness, and with no serious mental illness, 1990

Source: Kessler, Berglund, et al. (1998)
Surveys: National Cormorbidity Survey (NCS, 1990-92); Epidemiologic Catchment Area (ECA, 1980-85) and other surveys

Section 2: Characteristics of disability in adult life

Mental disorders can be disabling. For many adults with these disorders, the result is limitation in the ability to carry out regular day-to-day activities. For adults, an important daily activity is work. The employment rate for people with **mental illness** is much lower than the national employment rate, and is especially low for people with more serious disorders.

Topic Questions

For adults, how does mental illness rank as a cause of activity limitation compared to other conditions?

Do rates of psychiatric disorder differ for women and men?

Are there gender differences in limitations due to serious mental illness?

To what extent are people with mental illness employed?

Has labor force participation by people with mental illness changed over time?

To what extent does depression limit ability to work or carry out normal activities?

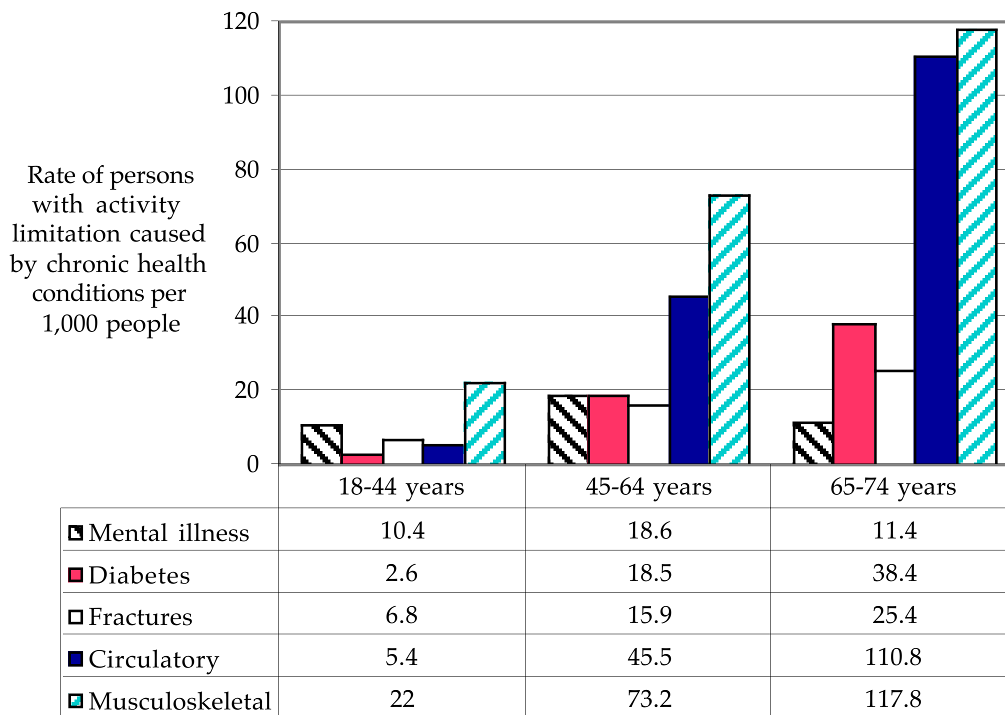
What are the conditions and symptoms of adults 65 years and older with mental disability?

To what extent do people 65 years and older with a mental disability have physical and communication disabilities?

For adults, how does mental illness rank as a cause of activity limitation compared to other conditions?

The relative importance of **mental illness** as a cause of **activity limitation** varies among different age groups. For younger adults, 18-44 years, mental illness was the second most frequently mentioned cause of activity limitation (10.4 per 1,000 people), exceeded only by musculoskeletal conditions (22 per 1,000). For mid-life adults, 45-64 years, mental illness ranked as the third most frequently mentioned cause of activity limitation in this age group (18.6 per 1,000). Relative to other conditions, mental illness was less frequently a cause of activity limitation for seniors, 65-74 years (11.4 per 1,000).

Among younger adults, 18-44 years, mental illness was the second most frequently mentioned cause of activity limitation.



	18-44 years	45-64 years	65-74 years
Mental illness	10.4	18.6	11.4
Diabetes	2.6	18.5	38.4
Fractures	6.8	15.9	25.4
Circulatory	5.4	45.5	110.8
Musculoskeletal	22	73.2	117.8

Figure 7: Selected chronic conditions causing activity limitation among adults 18-74, by age group

Source: National Center for Health Statistics (2002). Web site: http://www.cdc.gov/nchs
Survey: National Health Interview Survey, 1998-2000

Do rates of psychiatric disorder differ for women and men?

The **National Comorbidity Survey**, conducted in 1990-92, found that women and men experienced similar lifetime prevalence rates of **psychiatric disorder**. Among people between the ages of 15 and 54, nearly half of the women (47.3%) and the men (48.7%) experienced a psychiatric disorder at some point in their lives. However, women more often suffered a depressive disorder (23.9% of women; 14.7% of men) or anxiety disorder (30.5% of women; 19.2% of men). In contrast, substance abuse disorders affect more men (17.9% of women; 35.4% of men). Women were more likely to have experienced three or more psychiatric disorders in a lifetime.

Women and men have similar lifetime prevalence rates of psychiatric disorder, but rates differ for types of disorders.

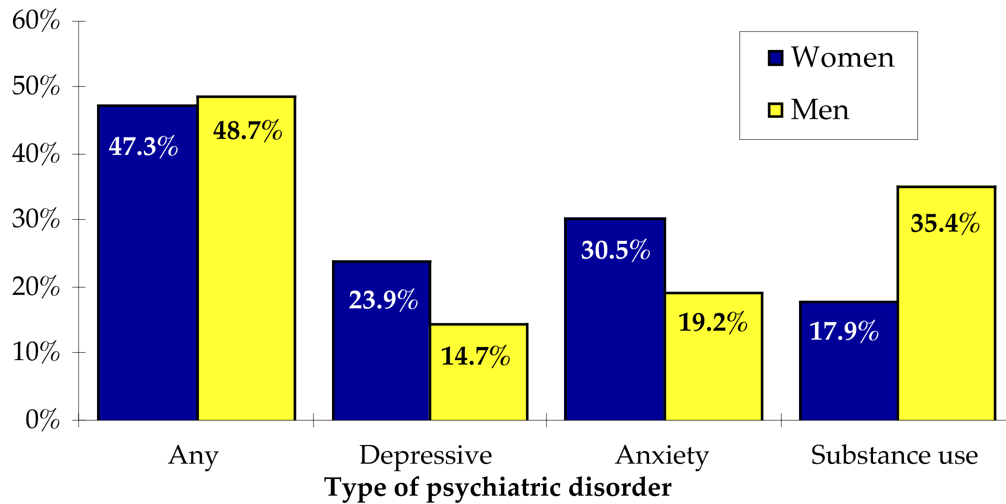


Figure 8: Lifetime prevalence of certain psychiatric disorders, by gender

Source: National Center for Health Statistics (1996); Kessler, McGonagle, & Zhao (1994)
Survey: National Comorbidity Survey, 1990-92

Are there gender differences in limitations due to serious mental illness?

The most recent Mental Health Supplement to the **National Health Interview Survey (NHIS-MH)** conducted in 1989 shows that among people between the ages of 25 and 64 who reported a **serious mental illness**, a large majority also reported disability (in the form of limitations in non-work-related activities). A higher percentage of men (87.0%) than women (71.3%) reported any non-work-related limitations. The most frequently reported limitation was a reduced ability to cope with daily stress (79.1% of men; 65.9% of women). More men (60.0%) than women (41.9%) reported that their mental illness interfered with their social functioning. Similarly, 59.2% of men with serious mental illness reported limitations in their ability to concentrate on tasks, compared to 41.4% of women. Finally, more than a third (34.7%) of men, compared to only 16.9% of women reported limitations in their ability to perform **instrumental activities of daily living (IADLs**), such as shopping and managing money.

Among those with serious mental illness, men are more likely than women experience limitations due to their mental illness.

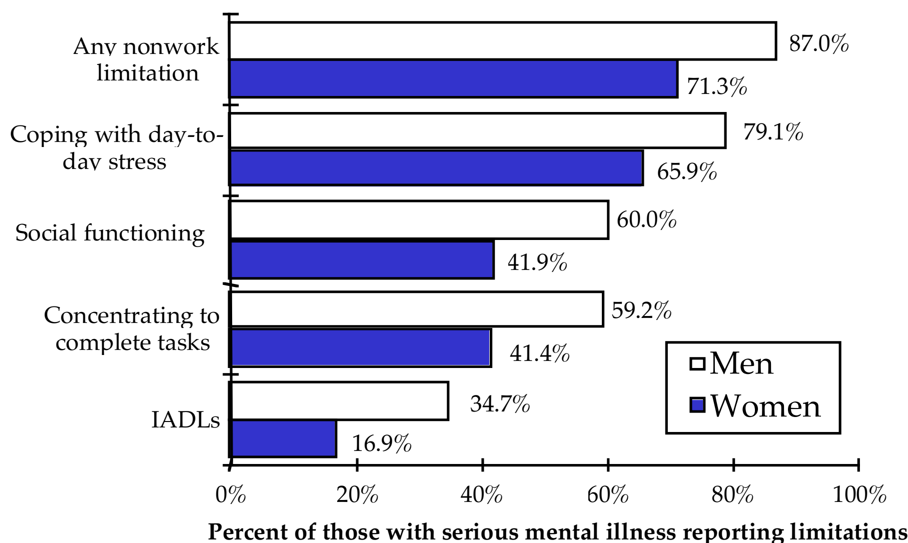


Figure 9: Percentage of men and women with serious mental illness reporting limitations in non-work-related activities

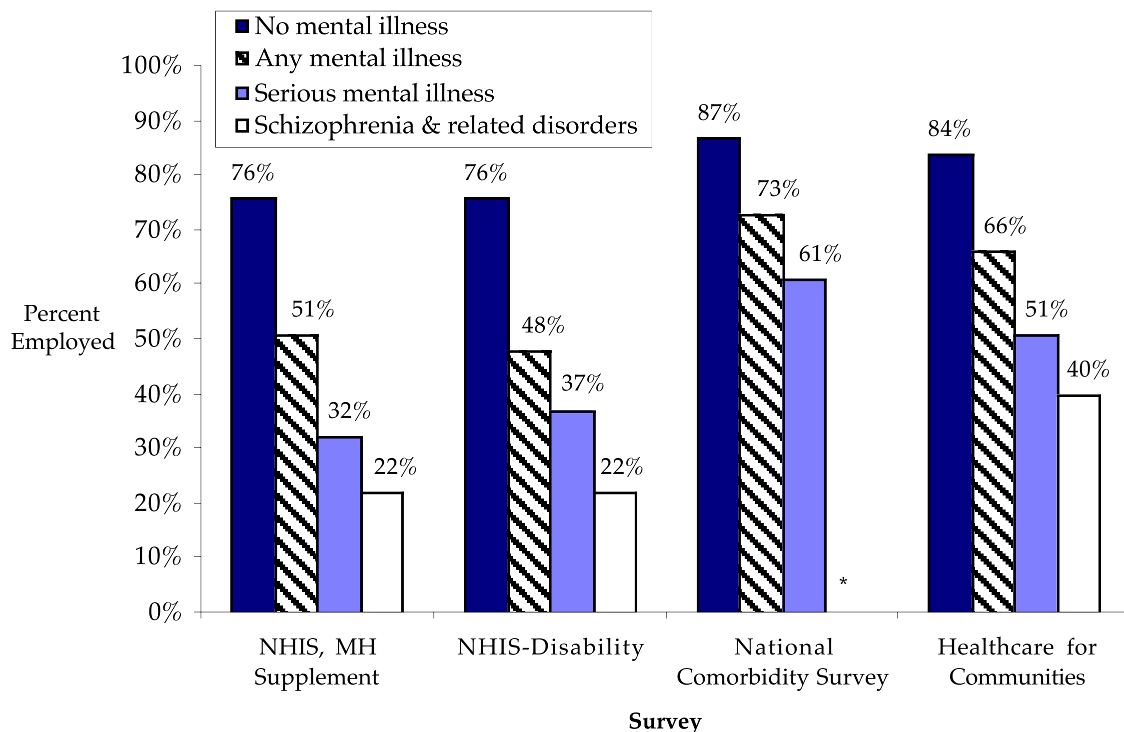
Source: National Center for Health Statistics (1996)
Survey: National Health Interview Survey, Mental Health Supplement (NHIS-MH), 1989

To what extent are people with mental illness employed?

In four nationally representative surveys conducted between 1989 and 1998, people with any **mental illness** had lower employment rates (48% to 73%)[†] than people who did not report mental illness (76% to 87%). Employment rates for people who reported **serious mental illness** were even lower, ranging from 32% to 61%. Among those with serious mental illness who had schizophrenia and related disorders, employment rates ranged from 22% to 40%.

Analysis of the **NHIS-D** shows that employed people with mental illness worked in a range of occupational categories similar to those of people with no mental illness. Among people with mental illness, as in the general population, educational attainment was the strongest predictor of employment in high-level occupations.

People with any mental illness are employed at lower rates than people with no mental illness; rates for people with serious mental illness are even lower.



* insufficient cases
[†]source data reported without decimal places

Figure 10: Percentage employed among adults with and without mental illness in 4 nationally representative surveys, 1989-98

Source: Mechanic, Bilder, & McAlpine (2002)
Surveys: NHIS-Mental Health Supplement, 1989; National Comorbidity Survey (NCS), 1990-92; NHIS-D, 1994-95; Healthcare for Communities, 1997-98

Has labor force participation by people with mental illness changed over time?

Between 1983 and 1994, **labor force participation rates** for people ages 18-64 with **mental illness** increased by 18% from 22.4% to 27.2%. However, during that time, the prevalence of mental illness doubled from 758,000 to more than 1.4 million people.

In that same 12 year period, labor force participation of people with mental illness lagged consistently behind participation of people with any disability (which ranged from 48.6% in 1983 to 51.8% in 1994) and far behind participation of people with no disability (79.1% in 1983 to 83.0% in 1994).

The study also found that labor force participation rates were consistently lower for people who had both mental illness and another condition, compared to people with mental illness only.

Labor force participation of people with mental illness has been consistently lower than that of others.

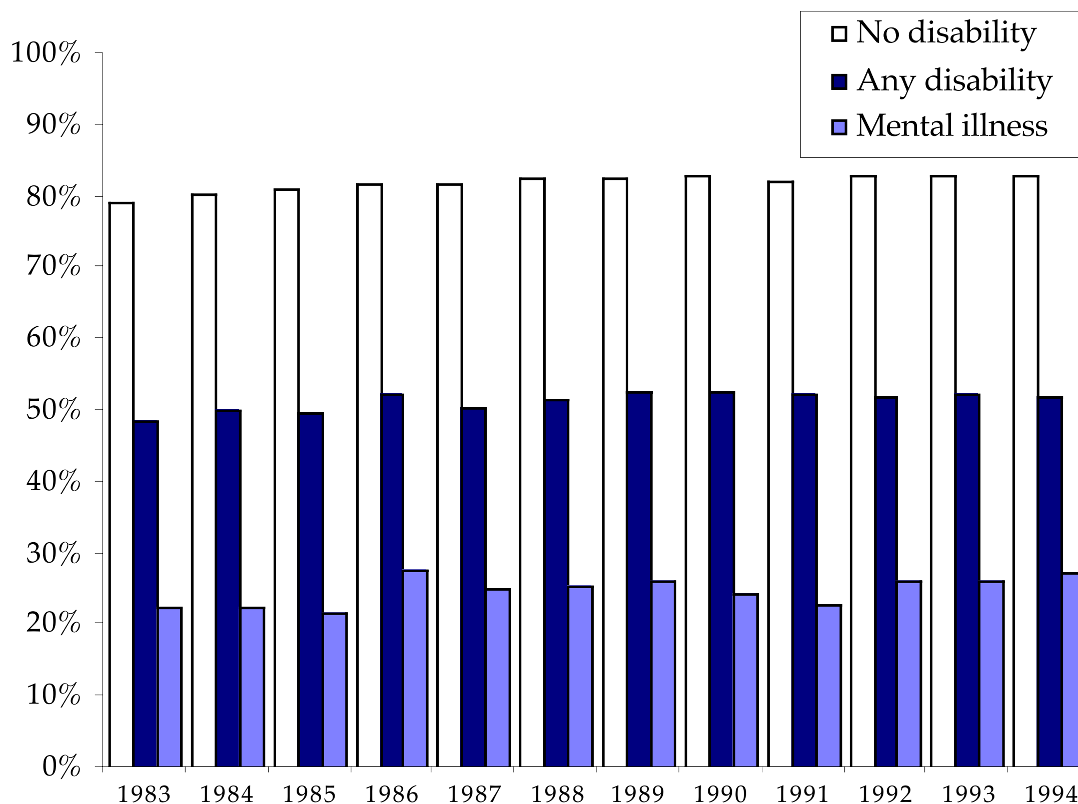


Figure 11: Labor force participation rates for people with mental illness, with any disability, and with no disability, from NHIS 1983-1994

Source: Source: Trupin, Sebesta, Yelin, & LaPlante (1997)
Survey: Survey: NHIS, 1983-94

To what extent does depression limit ability to work or carry out normal activities?

The **National Comorbidity Survey Replication (**NCS-R, 2001-2002) estimates that 32.6 to 35.1 million adults (16.2%) experience **major depressive disorder** at some point in their lives. Major depressive disorder is a serious disorder that is different from normal temporary feelings of sadness. An estimated 13.1 to 14.2 million adults (6.6%) experience major depressive disorder within a given year.

Adults with major depressive disorder in the past twelve months reported an average of 35.2 days in the past year that they were totally unable to work or carry out normal activities due to depression. Those with very severe **role impairment** missed an average of 96.5 days of work or normal activities.

Adults with major depressive disorder were unable to work or carry out their normal activities for an average of 35.2 days per year.

Figure 12: Mean number of days that respondents were unable, due to depression, to work or carry out normal activities in past year, by severity of role impairment

Source: Kessler, Berglund, Demler, et al. (2003)
Survey: National Comorbidity Survey Replication (NCS-R), 2001-2002

What are the conditions and symptoms of adults 65 years and older with mental disability?

More than 1.72 million people 65 years and over (5.4% of that population) reported one or more mental conditions. The main selected conditions were "Alzheimer's, senility, or dementia" (1.22 million people, 3.8% of the population 65 years and over); and "other mental or emotional conditions" (506,000, 1.6%).

About 1.68 million people (5.3%) reported one or more mental symptoms that seriously interfered with the ability to manage day-to-day activities. The most common symptoms were "frequently anxious or depressed" (1.26 million, 3.9%), "trouble coping with stress" (971,000, 3.0%), and "trouble concentrating" (967,000, 3.0%).

Another 2.4 million people 65 and over (7.5%) reported "difficulty keeping track of money and bills."

Of people 65 years and over, 5.4% had one or more mental conditions, 5.3% had mental symptoms that interfered with daily activities, and 7.5% had difficulty keeping track of money and bills.

	People age 65 years and older	
	Number	**Percent**
With a mental disability	**3,912,000**	**12.2%**
With 1 or more selected conditions	**1,722,000**	**5.4%**
A learning disability	210,000	0.7%
Mental retardation	114,000	0.4%
Alzheimers, senility or dementia	1,219,000	3.8%
Other mental/emotional condition	506,000	1.6%
With 1 or more selected symptoms that seriously interfered with everyday activities	**1,684,000**	**5.3%**
Frequently depressed or anxious	1,256,000	3.9%
Trouble getting along with others	325,000	1.0%
Trouble concentrating	967,000	3.0%
Trouble coping with stress	971,000	3.0%
Had difficulty keeping track of money and bills	**2,402,000**	**7.5%**

Figure 13: Percentage of people age 65 and over with mental conditions, with symptoms that interfere with everyday activities, and with difficulty keeping track of money/bills

Source: McNeil (2001)
Survey: SIPP, 1997

To what extent do people 65 years and older with a mental disability have physical and communication disabilities?

Nearly 4 million people 65 years and older had a **mental disability** in 1997 (3,912,000, or 12.2% of the population 65 years and over). There were 203,000 with a mental disability alone (0.6%), 137,000 with a mental and communication disability (0.4%), 1,403,000 with a mental and physical disability (4.4%), and 2,168,000 with a disability in all three domains (6.8%). The **SIPP** category of mental disability includes people with mental retardation, learning disabilities, and dementias — groups that are not generally included in the data reported in this chartbook.

Most people 65 years and older with mental disability have other disabilities.

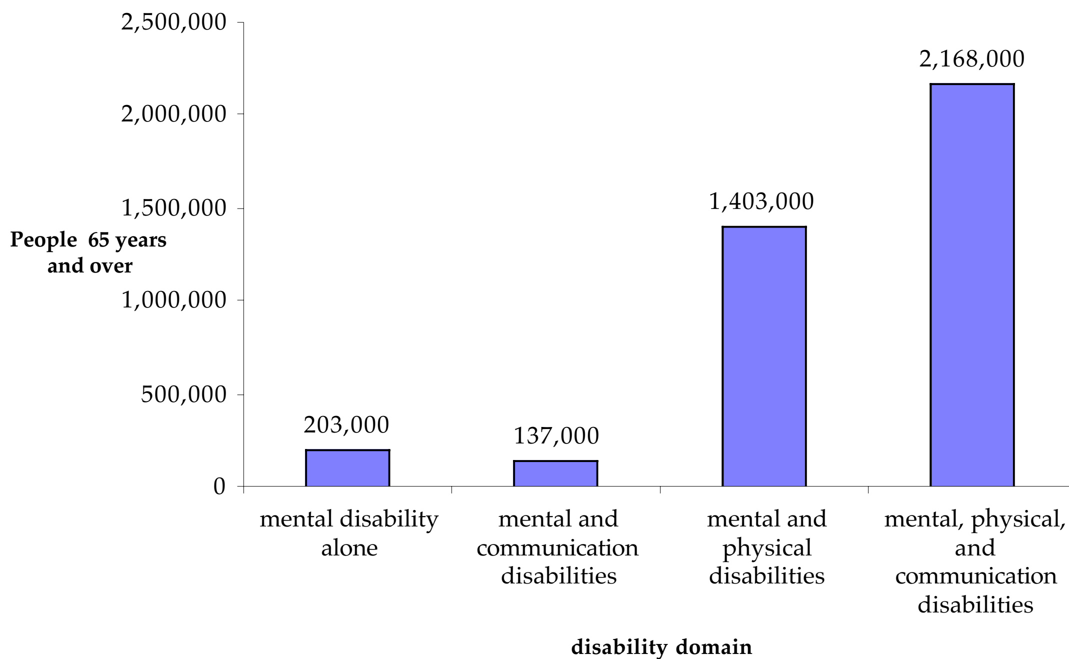


Figure 14: Number of people age 65 years and over with mental disability, and mental disability in combination with physical and communication disabilities

Source: McNeil (2001)
Survey: SIPP, 1997

Section 3: Children and mental health disabilities

There are varying estimates of how many children have limitations due to mental disorders, depending on the way that the disorders are defined and measured. Almost ten percent of the children in the **special education** system are identified as having **emotional disturbance**, a term that covers many mental disorders, and the rate is highest for teenagers. These students have higher **dropout rates** than other students, and are less likely to successfully complete high school.

Topic Questions

How many children and youth have mental or emotional problems or behavioral functional limitations?

How many children in special education have emotional disturbance?

Do rates of emotional disturbance differ by age group?

Do boys and girls experience different rates of emotional disturbance?

Do dropout and graduation rates differ for youth with emotional disturbance compared to youth with other disabilities?

What is the risk of suicide among youth?

How many children and youth have mental or emotional problems or behavioral functional limitations?

The **National Health Interview Survey on Disability (NHIS-D**) describes the U.S. population of children with mental or emotional problems, as well as selected behavioral **functional limitations** related to paying attention, school behavior and communicating and getting along with others. Children who had these problems or limitations were included in the "Disability Group," while those without were in the "Reference Group."

Using this data, 8.2% of civilian, non-institutionalized children age 5-17 years old in the United States (4.1 million children) were estimated to be in the "Disability Group." Of these children, 2.8 million are boys, while 1.3 million are girls.

Within the Disability Group, 54.3% (an estimated 2.2 million children) have functional limitations only, 32.8% (1.3 million) have functional limitations and mental or emotional problems, and 12.9% (529,000) have mental or emotional problems only.

More than 4.1 million children and youth have these problems or limitations, with more boys than girls reporting such disabilities.

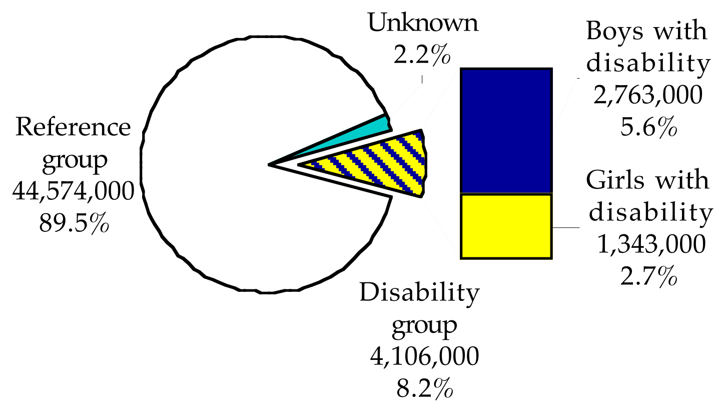


Figure 15: Percentage and number of children in Disability Group (by gender) and Reference Group, U.S. civilian non-institutionalized population, 5-17 years

Source: Colpe (2000)
Survey: National Health Interview Survey on Disability (NHIS-D), 1994-96

How many children in special education have emotional disturbance?

Emotional disturbance was the disability category for over 8% of children and youth with disabilities ages 6-21 who received special education services under **IDEA** in the 2000-2001 school year (472,932 of 5,762,935 students with disabilities).*

About 1 in 12 students served under IDEA has emotional disturbance.

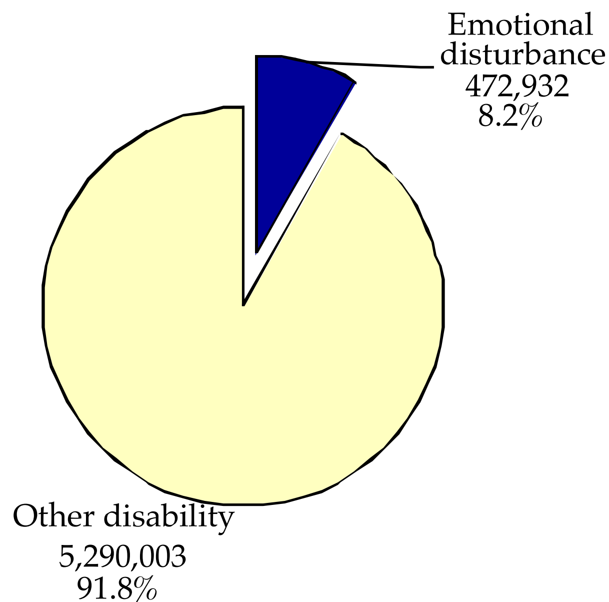


Figure 16: Number and percentage of students age 6-21 with emotional disturbance served under IDEA for school year 2000-2001

*Includes the 50 states, District of Columbia, and Puerto Rico

Source: U.S. Department of Education, OSERS (2002)
Survey: U.S. Department of Education, OSEP, Data Analysis System

Do rates of emotional disturbance differ by age group?

Data from school year 1995-96 show that only 3.5% of students with disabilities ages 6-7 were identified as having **emotional disturbance**; this percentage increases for each age group to 13% of students with disabilities in high school years (13.1% for ages 14-15; 13.0% for ages 16-17).

Overall, in the United States, an estimated 10.8% of children ages 6-17 were served by **IDEA**. Emotional disturbance was identified in .92% of the overall student population nationwide, although predicted prevalence is closer to 2%. States vary greatly in the rate of identification of emotional disturbance, from .06% to almost 2%, reflecting different state practices.*

The percentage of students with disabilities identified as having emotional disturbance increases with age and is highest in the high school years.

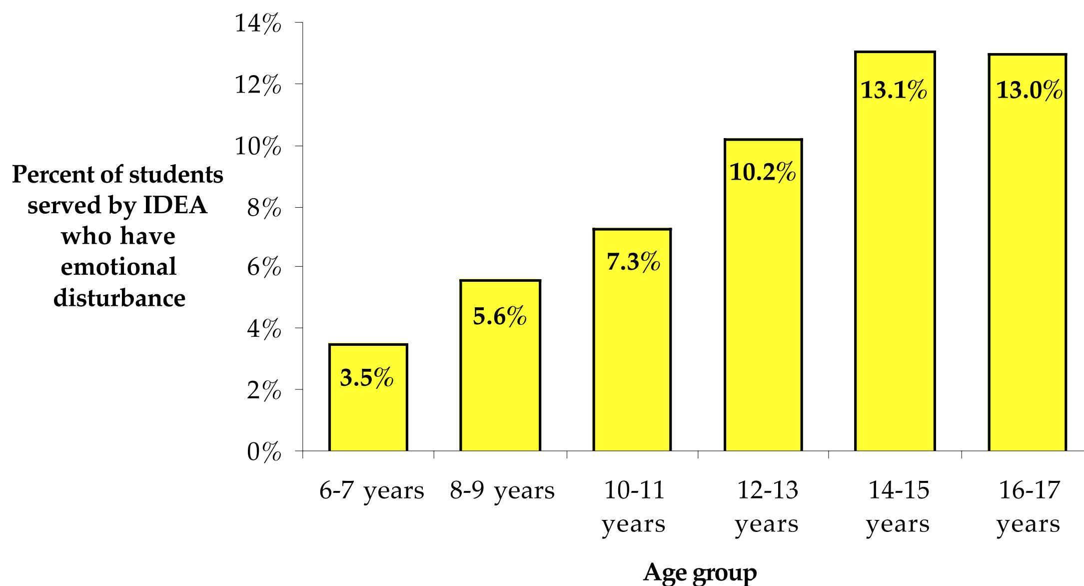


Figure 17: The percentage of students with disabilities identified as having emotional disturbance, by age group, 1995-1996

* States must specify criteria that are not inconsistent with the IDEA federal definition. The great range in identification rate is due, in part, to state interpretation of the federal definition based on their own standards, programs, and criteria.

Source: U.S. Department of Education, OSERS (1998), Section II: Students with Emotional Disturbance, and Table AA13, p. A-40
Survey: U.S. Department of Education, OSEP, Data Analysis System, 1995-96

Do boys and girls experience different rates of emotional disturbance?

More boys and young men in **special education** are reported to have an **emotional disturbance**, compared to girls and young women. In 1994, the Elementary and Secondary Schools Compliance Reports for the Office of Civil Rights show 79.4% of students with an emotional disturbance are males while only 20.6% are female. Similarly, the National Longitudinal Transition Study of Special Education Students found that 76.4% of students were male, and 23.6% were female.

More than three-fourths of students with emotional disturbance are boys.

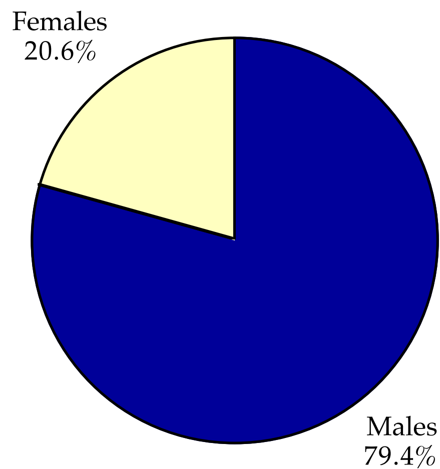


Figure 18: Gender of elementary and secondary-aged students with emotional disturbance

Source: U.S. Department of Education, OSERS (1998), p. II-27; Valdes, Williamson, & Wagner (1990).
Survey: U.S. Department of Education, Office for Civil Rights, 1994 Elementary and Secondary School Compliance Reports

Do dropout and graduation rates differ for youth with emotional disturbance compared to youth with other disabilities?

In school year 1998-99, the **drop-out rate** for students with **emotional disturbance** age 14 and over was 50.6% — the highest of any category of disability. (Specific learning disabilities was the next highest category at 27.1%.) There were 16,583 students with emotional disturbance who dropped out in that school year.

In that same school year, the **graduation rate** for students with emotional disturbance was 41.9%. There were 13,735 students with emotional disturbance that graduated with a standard diploma in that school year.

More than half of all youth with emotional disturbance dropped out of school, the highest rate among all disability categories.

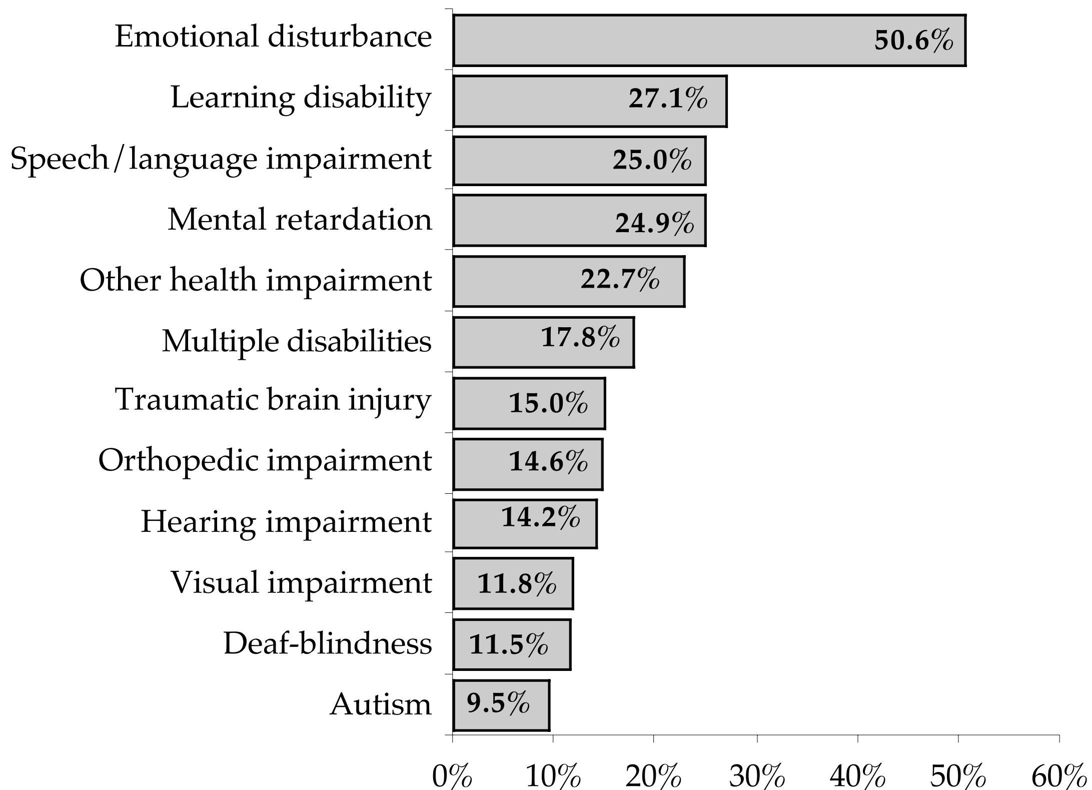


Figure 19: Number and percentage of students age 14 and older with disabilities who dropped out, by selected disability categories

Source: U.S. Department of Education, OSERS (2001), Table I-1
Survey: U.S. Department of Education, OSEP, Data Analysis System, 1998-99

What is the risk of suicide among youth?

In the second half of the 20th century, the suicide rate among young people increased dramatically. Between 1952 and 1995, the incidence of suicide among adolescents and young people nearly tripled. In 2000, people under the age of 25 accounted for 15% of all suicides. For young people 15-24 years old, suicide is among the three leading causes of death, after unintentional injury and homicide.

Every two years, the **Youth Risk Behavior Survey** asks high school students nationwide about sadness, suicide ideation and attempts during the past year. In 2001, 28.3% of students had felt so sad or hopeless almost every day for more than two weeks that they stopped doing usual activities. Nearly one in five (19.0%) had seriously thought about attempting suicide, and 14.8% had made a specific suicide plan. Nearly nine percent (8.8%) had made one or more actual suicide attempts, and 2.6% had made an attempt that required medical attention in the past year.

Almost one in five adolescents has seriously thought of suicide, and nearly 9% report a suicide attempt.

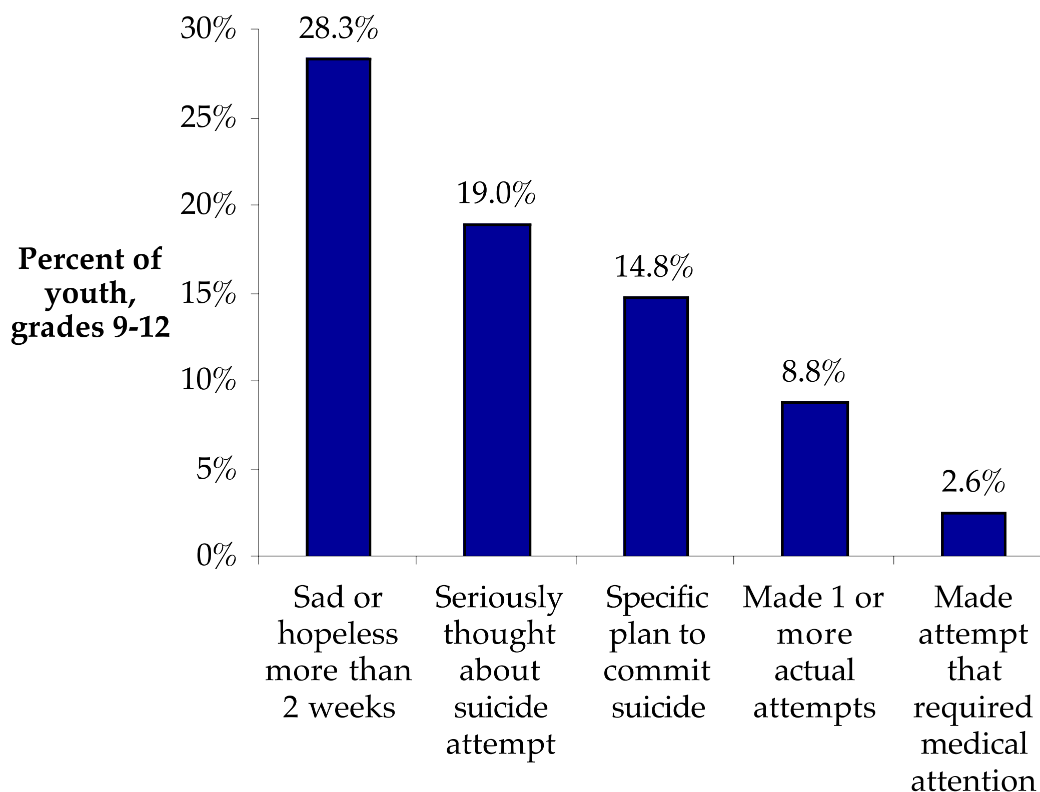


Figure 20: Percentage of youth, grades 9-12, who reported sadness and suicide risk, 2001

Source: Grunbaum, et al. (2002); National Center for Injury Prevention and Control (2003)
Survey: Youth Risk Behavior Survey (YRBS), 2001

Section 4: Access, utilization, and cost of services

Many resources, benefits, and services are available to address the needs of people with **disability due to mental disorder** and to reduce or eliminate barriers to full participation in school, work and other activities. Not all people with disability due to mental disorder, however, have access to services, treatment, and medication. The need for services and resources is apparent in the increases in demand for Social Security support, and in the use of **Vocational Rehabilitation**, **Independent Living Centers**, and nursing homes. The service system in general is not adequate to meet all the needs. This is reflected in the numbers of people with mental disorders who are homeless, and the extent to which both juveniles and adults receive services through prisons and jails rather than from mental health organizations. The shortfall in appropriate treatment and services results in lost productivity, lost lifetime earnings, and cost of care for people with **mental disorders**.

Topic Questions

Does use of mental health services by people with mental health disability differ by age?

How many children and youth use mental health services?

Does level of education affect use of mental health services?

What percentage of people with serious mental illness receives minimally adequate treatment?

What percentage of people who receive Social Security disability benefits has a mental disorder?

Has the number and percentage of people receiving SSI for a mental disorder changed over time?

How many people with a primary disability of mental disorders are served by Vocational Rehabilitation?

What percentage of Independent Living Centers serves people with a primary disability of mental illness?

How many people in nursing homes have a mental disorder?

How many homeless people have disabilities due to mental disorders?

How many people with mental disorders are in correctional institutions?

What kinds of mental health services are provided in state prisons?

How many jails provide essential mental health services?

What kinds of mental health services are provided in the juvenile justice system?

How do mental disorders affect the U.S. economy?

Does use of mental health services by people with mental health disability differ by age?

It is estimated that 29% of adults with a **mental health disability** receive mental health services in a year. Age appears to be a major factor in receipt of mental health services. The age groups of 25-34 years and 34-44 years show the highest service use, 37.8% and 38.7% respectively. With age, those levels drop: 32.4% for 45-54 year olds, 27.5% for 55-64 year olds, 18.1% for 65-74 year olds, and 2.6% for those 75 and older. Younger people also have low service usage with only 23.7% of 18-24 year olds with a mental health disability receiving services.

Older people and young adults receive less mental health treatment for their mental disorders.

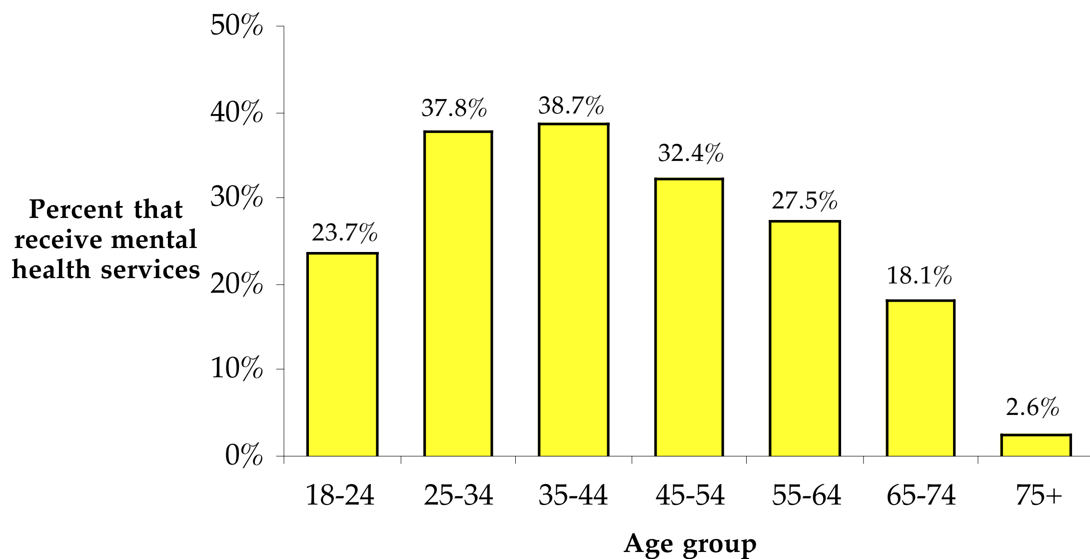


Figure 21: Use of mental health services by adults with mental health disability, by age group

Source: Kaye (2001)
Survey: NHIS_D, 1994-95

How many children and youth use mental health services?

More than 1.3 million children under the age of 18 years – about one in 50 children – received mental health services in the U.S. in 1997. This is almost double the number of children who received those services in 1986. These estimates, based on the **Center for Mental Health Services (CMHS) Client Patient Sample Survey**, include only children seen in community mental health settings. The estimates are conservative as they do not include youth who consulted exclusively with individual therapists and paid for the treatment with private insurance or personal funds.

Of the children and youth receiving mental health services, 50.7% were adolescents aged 13-17 years, 40.3% were elementary school-aged children aged 6-12 years and 9.1% were pre-schoolers, aged 0-5 years. More boys (56.0%) than girls (44.0%) received mental health services.

More than 1.3 million children and youth receive mental health services, and the rate has nearly doubled in a decade.

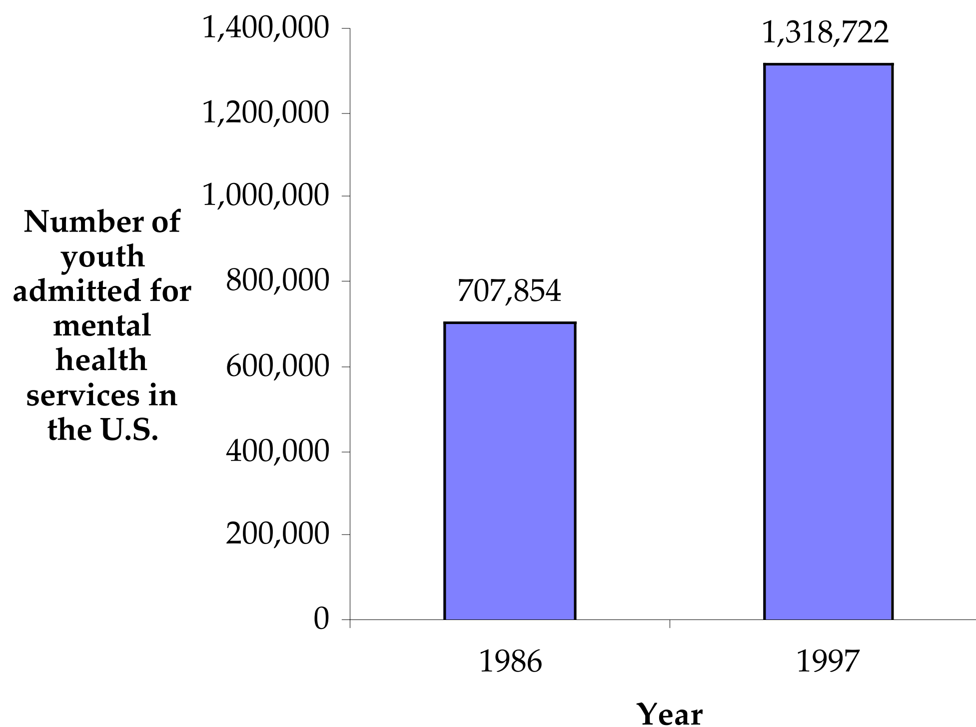


Figure 22: Number of youth admitted for mental health services in the U.S., 1986 and 1997 estimates

Source: Pottick (2002); Pottick, Warner, Manderscheid, & Elhosseiny (2003)
Surveys: National Institute of Mental Health data, 1986; Center for Mental Health Services, Client Patient Sample Survey, 1997

Does level of education affect use of mental health services?

Level of education has a large impact of the use of mental health services for those with a **mental health disability**. Only 21.0% of non-high school graduates with mental health disabilities received mental health services. In contrast, about twice as many college graduates with mental health disabilities received mental health services (42.4%). High school graduates were in between, with 32.6% receiving services.

Among those with mental health disabilities, those who have more education are more likely to receive treatment.

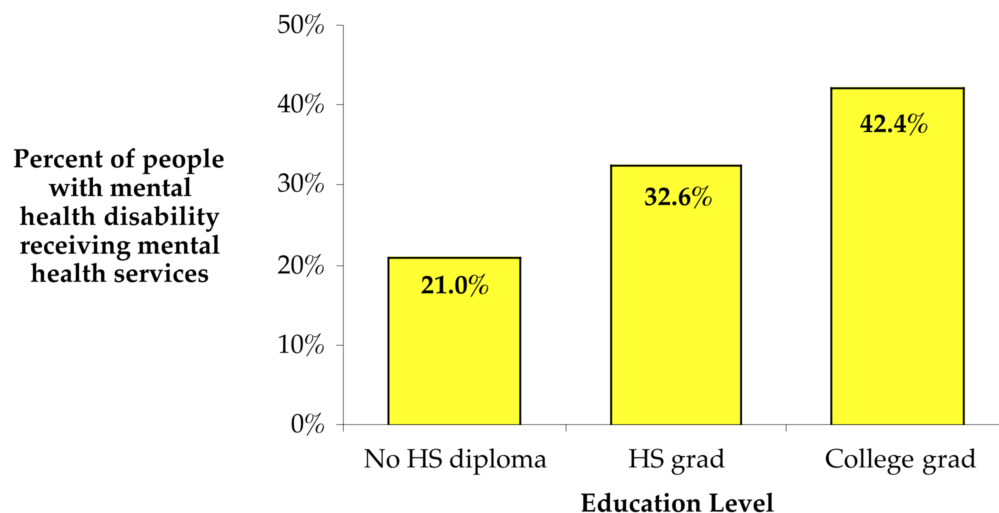


Figure 23: Percentage of people with mental health disability receiving mental health services, by level of education

Source: Kaye (2001)
Survey: NHIS_D, 1994-95

What percentage of people with serious mental illness receives minimally adequate treatment?

While it is estimated that nearly 40% of people with **serious mental illness** receive treatment, only 15.3% receive "minimally adequate treatment." Minimally adequate treatment includes either 1) the appropriate medication for the type of disorder and 4 or more visits with a physician or mental health specialist, or 2) when appropriate, 8 or more visits with a mental health specialist.

On the basis of these findings and 1999 U.S. Census data, it is estimated that more than 8.5 million people with serious mental illness do not receive minimally adequate treatment each year.

Only 15.3% of those with serious mental illness receive minimally adequate treatment.

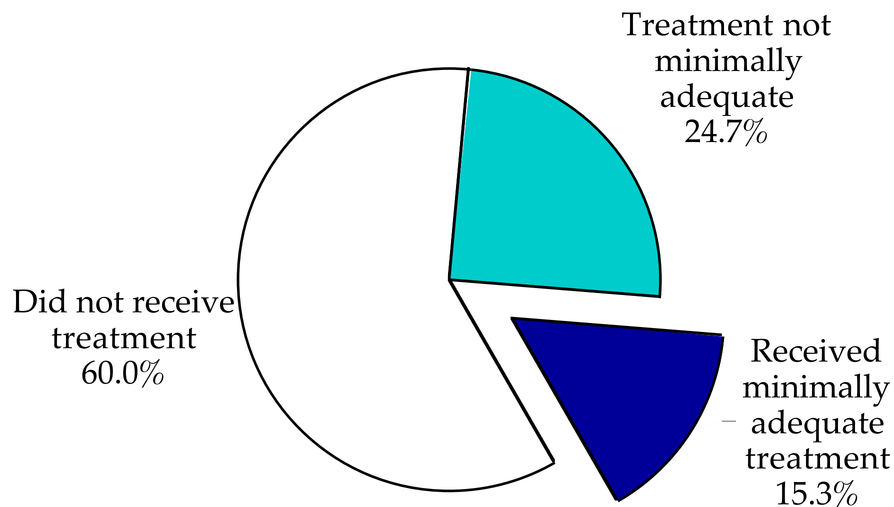


Figure 24: Percentage of people with serious mental illness receiving different categories of treatment

Source: Wang, Demler, & Kessler (2002)
Survey: National Comorbidity Survey, 1990-92

What percentage of people who receive Social Security disability benefits has a mental disorder?

According to the **National Health Interview Survey on Disability (NHIS-D)**, about 4.3 million people receive some form of disability benefits (including both federal benefits and disability pensions) for a mental disorder. This represents about 18.3% of people with **mental disorders**, or about 1.7% of the U.S. population.

Most people who receive disability benefits for a mental disorder are covered under one of two Social Security benefit programs, Social Security Disability Insurance (**SSDI**) and/or Supplemental Security Income (**SSI**).

Mental disorders that prevent substantial gainful employment (including mental retardation) are the leading reason that people receive both SSI and SSDI. Mental impairments also are associated with the longest entitlement periods.

In 2001, 28.0% of SSDI recipients and 35.4% of SSI recipients received payment based on a mental disorder (not including mental retardation).

More than one in four SSDI recipients and one in three SSI recipients has a mental disorder.

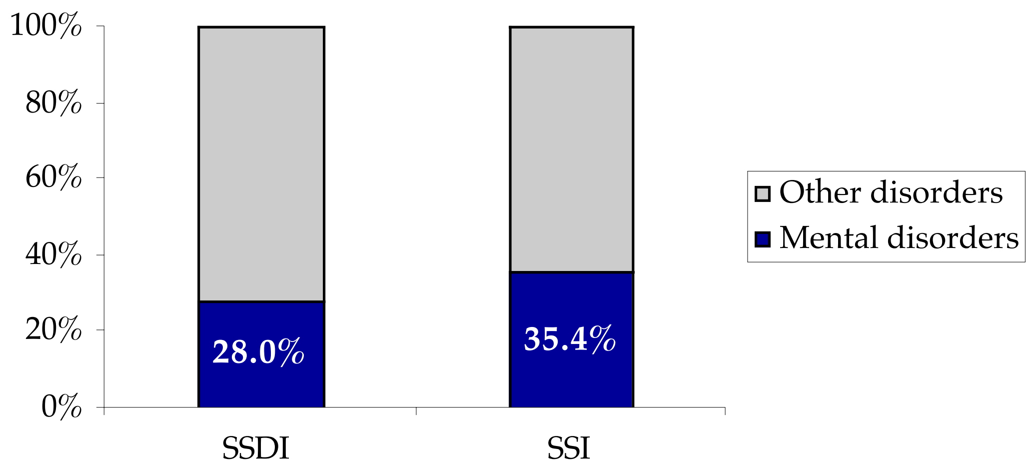


Figure 25: Percentage of people with mental and other disorders receiving SSDI and SSI

Source: Social Security Administration (2002)
Survey: Social Security Program Administration Data, 2001

Has the number and percentage of people receiving SSI for a mental disorder changed over time?

From 1988 to 2001, the total number of people receiving **SSI** rose more than two and one-half times, from about 1.7 million to 4.3 million. During the same period, the number of SSI recipients with mental disorders more than tripled from 411,800 in 1988 to 1.5 million in 2001. About one in four SSI recipients (24.5%) had a mental disorder in 1988, increasing to 35.4% by the year 2001.

The percentage of "**disabled workers**" (**SSDI** recipients) with mental disorders has also grown over time, but not as rapidly as the SSI population.

The number and percentage of SSI recipients with mental disorders has increased from 1988 to 2001.

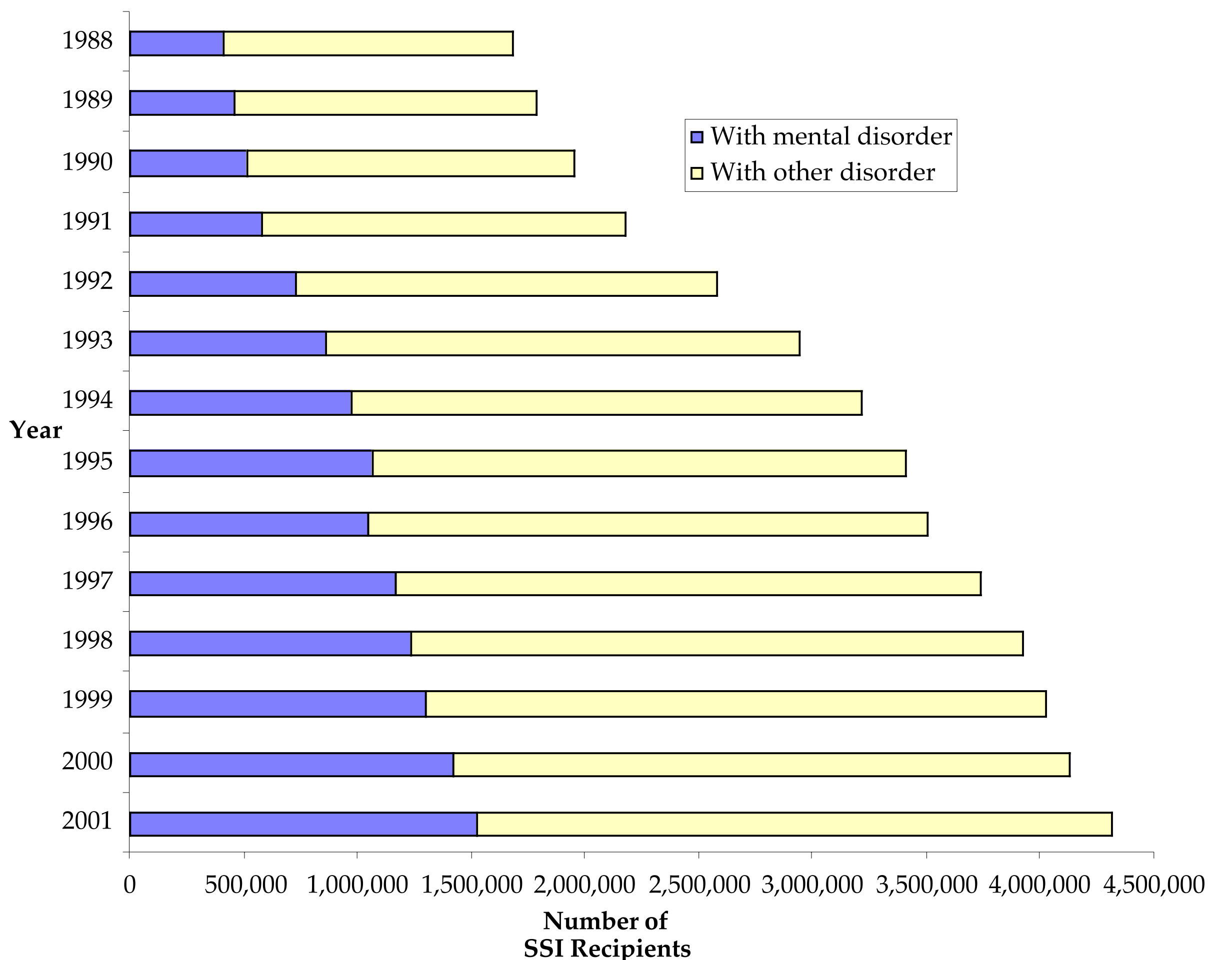


Figure 26: Number of SSI recipients with mental disorders vs. other diagnoses

Source: Social Security Bulletins (multiple years), Table 7.F.1
Survey: Social Security Program Administration Data

How many people with a primary disability of mental disorders are served by Vocational Rehabilitation?

Vocational Rehabilitation is another important service system for people with mental disorders. In FY2000, about 22.7% of the total number of clients who exited the **Vocational Rehabilitation** (VR) system had a primary disability of mental disorders (141,749 of 624,250). Among the group of VR clients with competitive or self-employment outcomes in 2000, 20.6% were people with mental disorders, autism, or traumatic brain injury as their primary disability (44,872 of 217,711).

About 1 in 5 successfully employed clients of Vocational Rehabilitation has a primary disability of mental disorders.

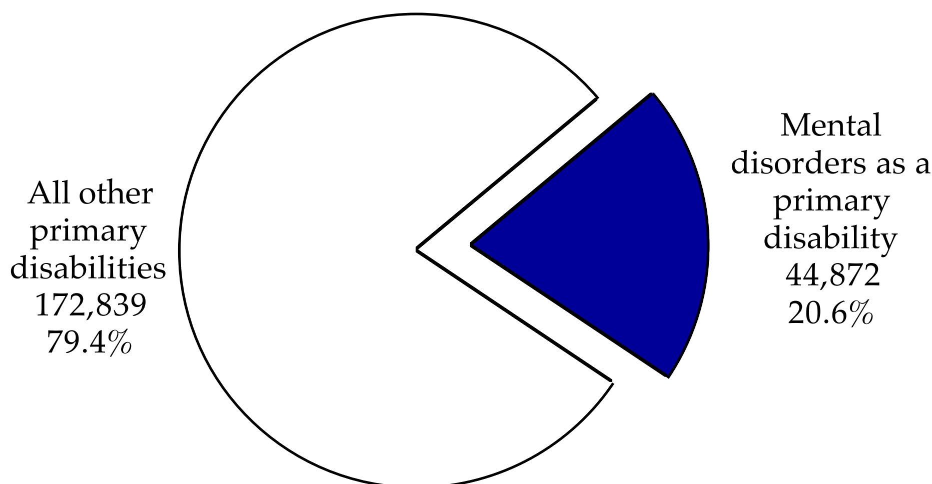


Figure 27: Number and percentage of successfully employed clients of Vocational Rehabilitation, by mental disorders as a primary disability and all other primary disabilities, 2000

Survey: Rehabilitation Services Administration Program Data, FY 2000
Source: Data analysis special run for Mental Health Services: Major Disability with Mental Health Conditions Specified by Closure Type and Work Status at Closure: FY 2000.

What percentage of Independent Living Centers serves people with a primary disability of mental illness?

Most Independent Living Centers (**ILCs**) provide some level of service to people who identify mental illness as their primary disability. In 1992, 86.1% of independent living centers reported serving people with a primary disability of mental illness, and this estimate increased to 94.8% in a 1995 follow-up survey.

During the same time period, ILCs reported an increase in the extent to which their centers had high involvement in mental health issues, from 28.8% of centers in 1992 to 41.7% of centers in 1995. High involvement ILCs met one or more of the following criteria: (1) the ILC reported that 20% or more consumers had a primary disability of mental illness; (2) the ILC served 100 or more consumers with a primary disability of mental ilness; (3) the ILC directly provided mental health services; and/or (4) the ILC named mental health issues as one of its top three program priorities.

Most Independent Living Centers provide services to people with mental illness as primary disability.

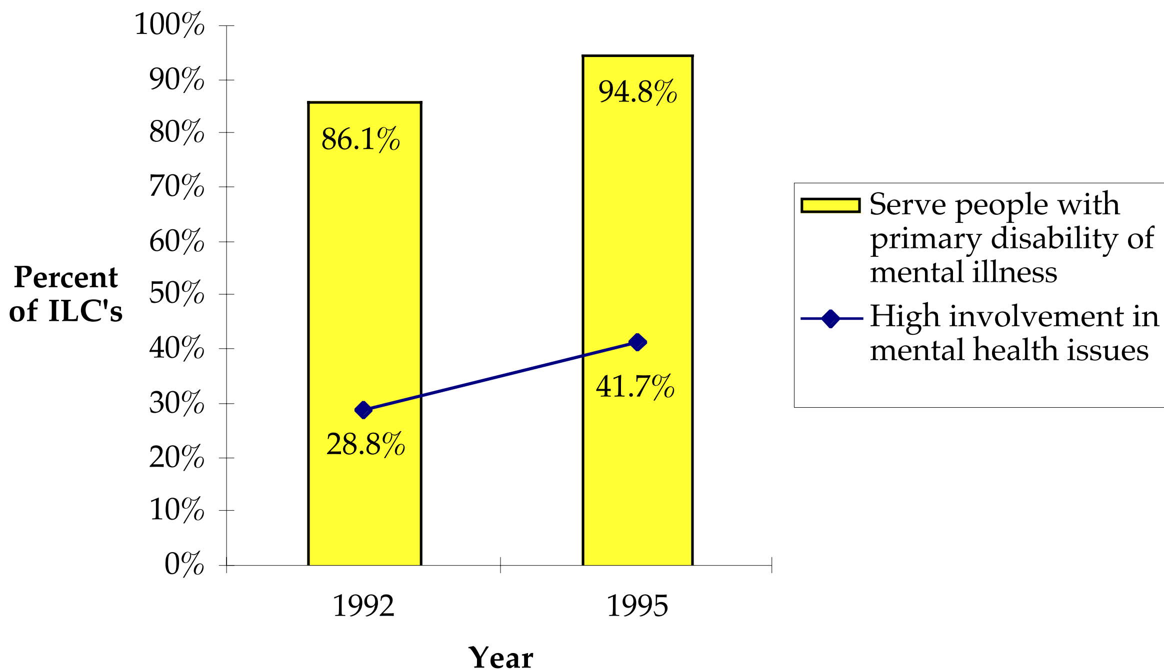


Figure 28: Percentage of Independent Living Centers providing services to people with a primary disability of mental illness, 1992 and 1995

Source: Benjamin, Stoddard, Jans, & Douglass (1997); Jans, Benjamin, Douglass, & Stoddard (1995)

How many people in nursing homes have a mental disorder?

The **National Nursing Home Survey** provides demographic information on people living in nursing homes. Of the approximately 1.5 million people who were 65 years and over and living in nursing homes in 1999, an estimated 236,300 (16.1%) had a **mental disorder** as their primary diagnosis when they were admitted. Other people in nursing homes may have mental disorders that were not their primary diagnosis upon admission, and others may have developed mental disorders after admission.

Over 20% of the 1,469,500 nursing home residents 65 years and over (315,400 people) received mental health services during the 30 days preceding the survey interview.

More than 16% of nursing home residents 65 years and over had mental disorders as their primary diagnosis at admission.

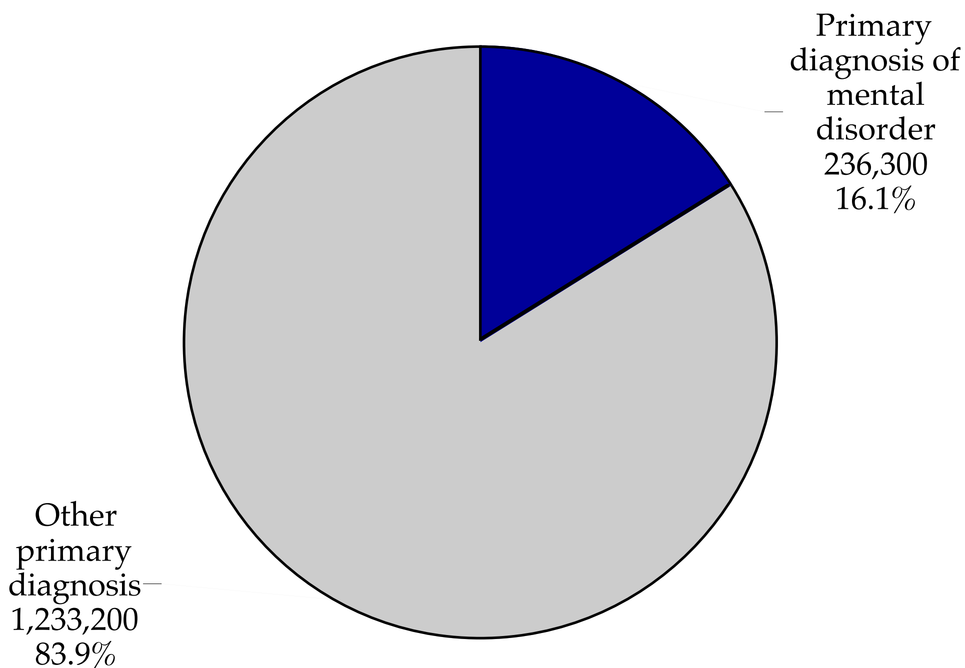


Figure 29: Percentage and number of nursing home residents with mental disorders as primary diagnosis at admission or another primary diagnosis, 1999

Source: Jones (2002)
Survey: National Nursing Home Survey, 1999

How many homeless people have disabilities due to mental disorders?

Up to 800,000 Americans are homeless on any given night. Each year, 2.3 to 3.5 million people (about 1% of the population) experience homelessness.

It is difficult to determine how many homeless people have **disabilities due to mental disorders**. Based on reviews of more than 160 homeless studies, the Federal Task Force on Homelessness and Severe Mental Illness estimated that at least one-third of homeless people have **severe mental illness**.

In a national survey of adults using homeless services, 75%* reported mental health or substance abuse problems. About 15% reported mental health problems only, 31% reported a combination of mental health and substance abuse problems and 29% reported substance abuse problems only.

Seventy-five percent of homeless adults reported mental health or substance abuse problems.

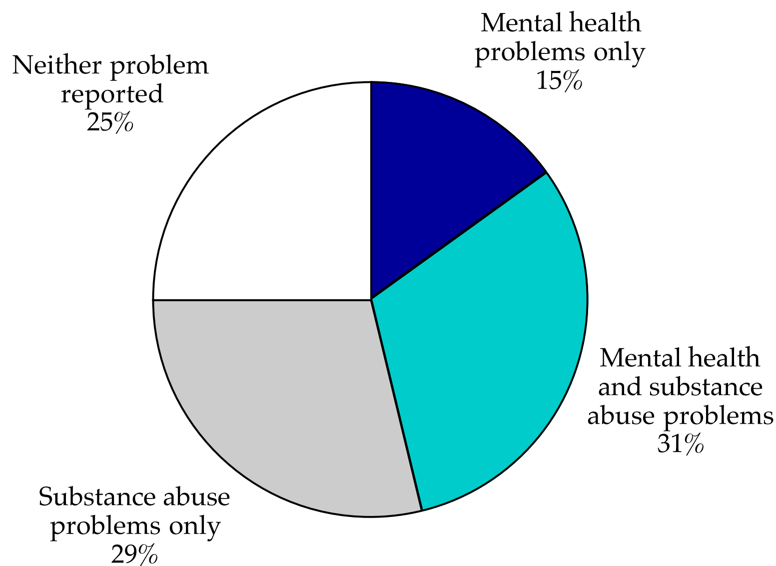


Figure 30: Percentage of adult homeless people reporting mental health problems, substance abuse problems and no problems, 1996

Source: Burt (2001); U.S. Bureau of the Census (1996); Federal Task Force on Homelessness and Severe Mental Illness (1992); Policy Research Associates (1997)
Survey: National Survey of Homeless Assistance Providers and Clients, 1996
*Source data reported without decimal places

How many people with mental disorders are in correctional institutions?

Correctional institutions – prisons, jails, and juvenile justice facilities – are, for some people with mental disorders, the first contact with mental health services. The Center for Mental Health Services has conducted nationwide surveys in the "de facto mental heath system" in correctional facilities to identify the extent of mental health services available there (Goldstrom, Henderson, Male, & Manderscheid, 1998).

At the close of 2001, nearly 2 million people (1,962,220) were held in federal or state prisons or local jails. An additional 108,931 youth were held in U.S. juvenile facilities. About 4.7 million adults were on probation or parole. In total, nearly 6.8 million people are under correctional supervision each year (Bureau of Justice Statistics, 2001; Bureau of Justice Statistics, 2003).

There are no clear prevalence data on the number of people in correctional institutions who have a **mental disorder** or a **disability due to mental disorders**, but a number of studies have found that the rate of mental disorders and disabilities is higher in these populations than in the general public.

On the basis of a 1997 inmate self-report survey, the Bureau of Justice Statistics estimated that 16.2% of state inmates (191,000) had a **mental illness** (Beck & Maruschak, 2001).

Teplin and her colleagues (1994, 1996, 1997) found that 9.0% of men and 18.5% of women entering local jails have a history of **serious mental illness**. They also found that 6.1% of men and 15% of women in local jails had current symptoms of serious mental disorders.

In a review of the literature on juvenile detention, Goldstrom and associates estimated that at least 20%* of youth in the juvenile justice system have **serious mental illness** and up to 75% have some mental emotional, or behavioral health problem (Goldstrom, Jaiquan, Henderson, Male, & Manderscheid, 2000).

* Source data reported without decimal places.

What kinds of mental health services are provided in state prisons?

In 2000, the **Census of State and Federal Adult Correctional Facilities** gathered data on mental health services from 1,668 federal, state and private prison institutions throughout the nation, which shows that more than 95% of state confinement prisons offered mental health services. Most state prisons screened inmates at intake (77.9%) and provided psychiatric assessment (78.8%). The state prisons also typically provided therapy or counseling (84.4%) and psychotropic medications (83.0%). A majority of state prisons maintained 24-hour mental health care in the facility (63.2%) and assisted released prisoners with mental health issues (72.0%). The lower security community-based facilities, which typically allow inmates to leave the facility unaccompanied, provided fewer services than the larger confinement facilities. Nevertheless, 82.2% of community-based facilities provided mental health services.

One in ten state inmates received psychotropic medications and 1 in 8 received mental health therapy or counseling.

Nearly all state prisons provide mental health services to prisoners; large state facilities provide more services than smaller, community-based facilities.

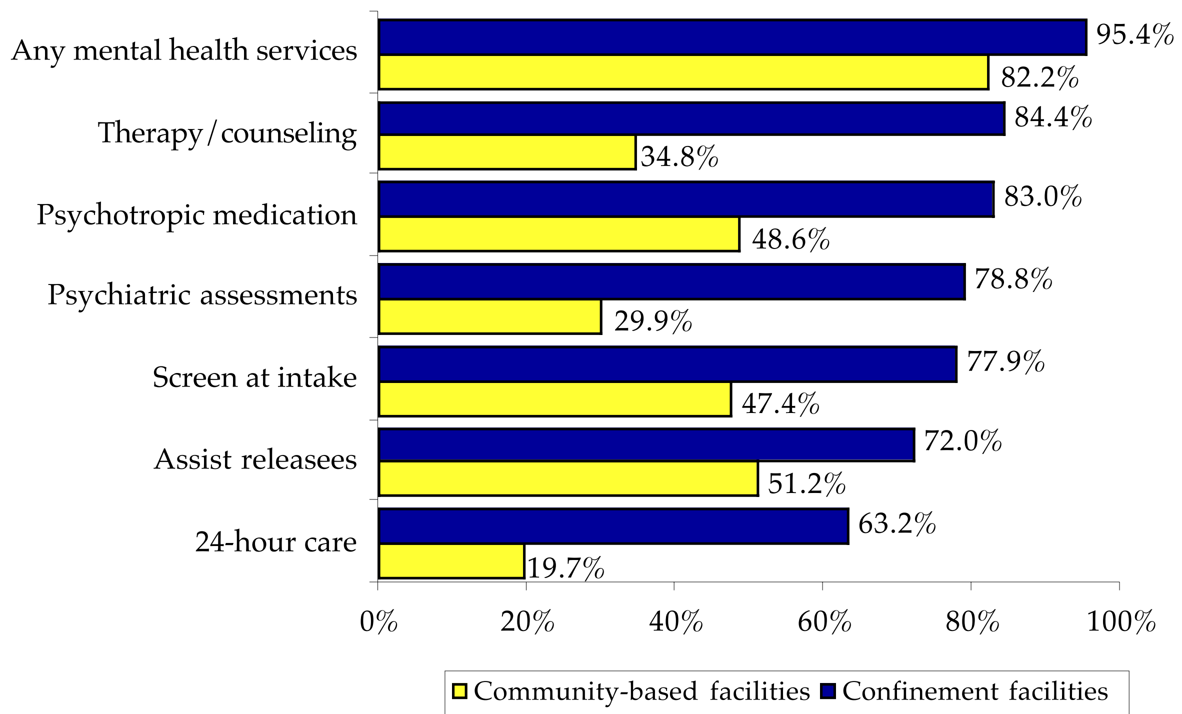


Figure 31: Percentage of state confinement prisons and community-based facilities providing selected mental health services, 2000

Source: Beck & Maruschak (2001)
Survey: Census of State and Federal Adult Correctional Facilities, 2000

How many jails provide essential mental health services?

In contrast to state prisons where inmates often stay for long periods of time, jails typically house people for short stays of 3 days or less, with most inmates leaving within 24 hours. Given that mental health treatment is not usually possible in such a short period, the Center for Mental Health Services (CMHS) defined four essential mental health services that are important for jails to provide: intake screening, evaluation, crisis intervention, and case management & discharge planning. CMHS used the 1993 **Inventory of Local Jail Mental Health Services** to assess how often jails provide these four essential mental health services. Among jails that provided any mental health services, slightly fewer than one-half (47%)* provided all four of the services. Larger facilities more often provided all of the essential services. Only about one-third of the smallest jails (Average Daily Population of less than 50 inmates) provided all essential mental health services. Among jails with at least 250 inmates on average each day, 75% or more provided all the essential mental health services.

Provision of essential mental health services varies by size of the jails.

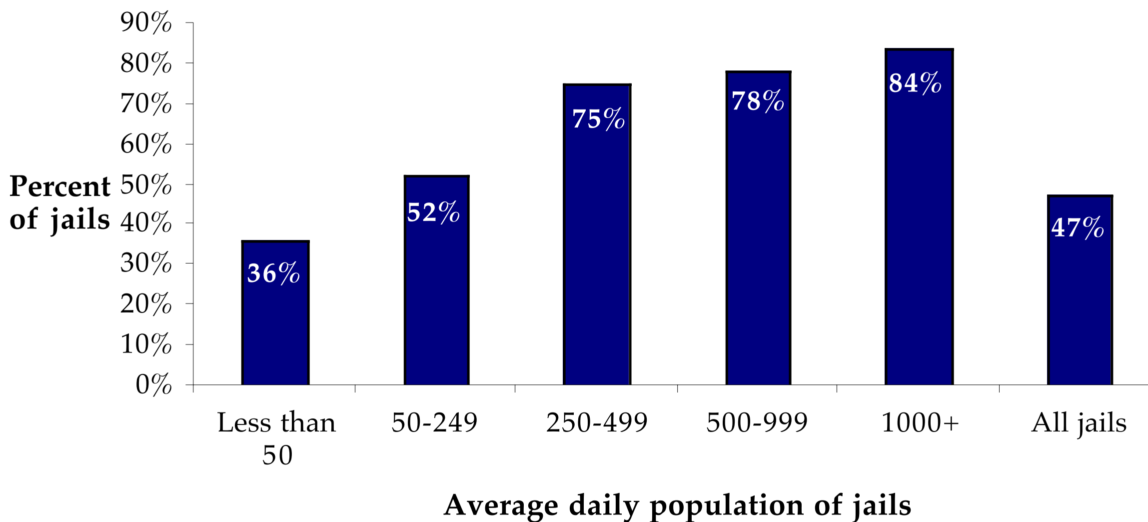


Figure 32: Percentage of jails providing 4 essential mental health services (screening, evaluation, crisis intervention, and case management) by Average Daily Population (ADP) of jails

Source: Goldstrom, Henderson, Male & Manderscheid (1998)
Survey: Inventory of Local Jail Mental Health Services, 1993
*Source data reported without decimal places

What kinds of mental health services are provided in the juvenile justice system?

The **Inventory of Mental Health Services in Juvenile Justice Facilities**, conducted in 1998, provides information on mental health services that are provided to youth in correctional institutions. The survey collected data from detention centers and shelters where youth are housed before adjudication, diagnostic centers where youth are evaluated, community based placements such as group homes and halfway houses, as well as institutional placements that include ranches, camps and farms, residential treatment facilities and training schools. Nearly all (94.3%) of these facilities provide mental health services to youth. The most common services available are medication (provided by 81.8% of the facilities), emergency mental health services (80.7%), evaluation (73.8%), therapy (69.0%) and mental health screening (64.2%). More than one-third of the facilities provide 24-hour mental health care (34.6%) and separate residential treatment for youth with mental health problems (37.1%).

Nearly all juvenile justice facilities provide psychotropic medication and emergency mental health services; approximately one-third provide 24-hour care and separate residential care.

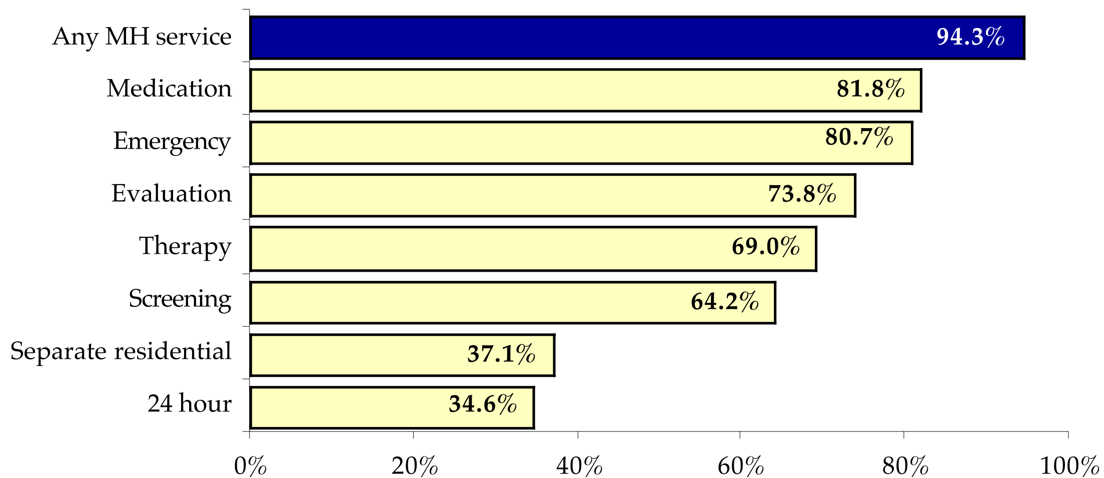


Figure 33: Percentage of juvenile justice facilities providing access to mental health services, by type of service, 1998

Source: Goldstrom, Jaiquan, Henderson, Male, & Manderscheid (2000)
Survey: Inventory of Mental Health Services in Juvenile Justice Facilities, 1998

How do mental disorders affect the U.S. economy?

The costs of mental disorder and disability due to mental disorder are staggering. An economic estimate of 1990 costs shows almost $150 billion dollars of direct and indirect costs and the estimates certainly would be higher today. The prevalence-based estimate includes direct medical costs of treatment and care, and indirect costs related to loss of productivity due to mental disorder.

Direct costs, obtained from national household interview and provider surveys and agency records, are estimated as the number of health and medical services for mental disorders, and the unit price or charges – a total of $67 billion. Other related direct costs total $2.3 billion and include public and private expenditure for crime ($1.8 billion) and social welfare programs ($515 million) associated with mental disorders.

Costs of reduced or lost productivity total $78.5 billion and include estimates of lost earnings ($59 billion), productivity losses of individuals in mental hospitals or in nursing homes due to mental disorders ($4.1 billion) or incarcerated in prisons as a result of a conviction for a mental disorder-related crime ($573 million), the value of time spent to care for family members with mental disorders ($3.1 billion), and expected value of future earnings or people who have died prematurely in 1990 from mental disorders, including all suicides ($11.8 billion).

Total economic cost of mental disorders in 1990 is almost $150 billion.

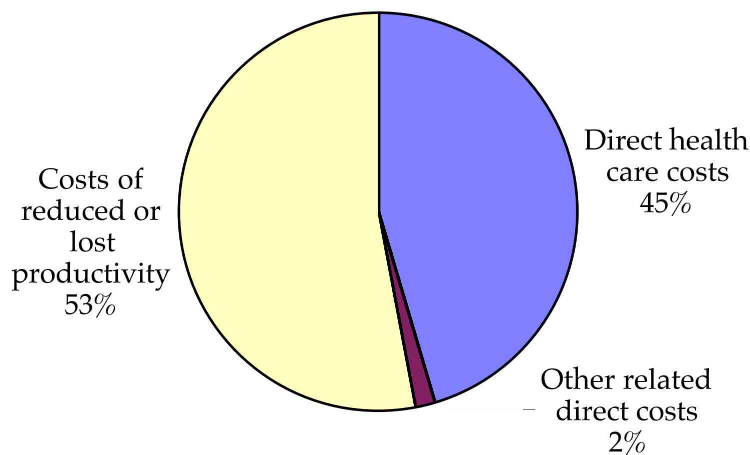


Figure 34: Estimated economic cost of mental disorders, 1990

Source: Rice & Miller (1998)
Surveys: Services - National Hospital Discharge Survey, National Nursing Home Survey, National Ambulatory Care Survey; Cost of services – American Hospital Association, American Medical Association, American Psychological Association, American Council of Social Workers, National Institute of Mental Health, national expenditure data from the Health Care Financing Administration, National Prescription Survey, Department of Justice Uniform Crime report, social welfare expenditures; Income loss - the Epidemiologic Catchment Area study (ECA); Earnings – U.S. Census; Caregiver time – Massachusetts Alliance for Mentally Ill.

Section 5: Research gaps and topics for further investigation of mental health and disability

This Chartbook is based on the best available information on mental health and disability. Available measures and statistics are limited by the specific surveys conducted by a range of federal agencies and research studies. As we developed this Chartbook, a number of information gaps became apparent. More work is needed to address those gaps and to improve our knowledge of the prevalence and needs of individuals with **disability due to mental disorders**.

First, there is incomplete and sometimes-contradictory information on prevalence, or estimates of how many people have a disability due to mental disorders. Until 2003, when information from the **NCS-R** began to be released, the only study that collected in-person information using established diagnostic measurement was the **ECA** survey, conducted between 1980 and 1985. While the ECA information was collected two decades ago, this study still provides important information on disorders, since self-reporting tends to undercount the prevalence of mental illness. Recent statistical work by Kessler and others shows that the ECA data provide good estimates that can be validated in other studies. While the ECA study was criticized for developing estimates based on only five U.S. locations, the estimates are still valuable. But with new medications and new attitudes regarding mental illness in the last fifteen years, it is time for new face-to-face data collection and new estimates of prevalence. Regardless of the study or survey method used, there is an undercount of actual prevalence due to reluctance to report stigmatizing conditions for one's self or for family members.

Some of the questions that need to be answered include:

- Is prevalence stable over time?
- Are some disorders increasing in prevalence?
- To what extent do available medication, treatment, and services reduce or eliminate the disabling impact of **mental disorders**?
- What accommodations are most effective in reducing barriers to school, work, and community?

Some of the needed information will come from scientific and genetic studies. But there is also a great deal that can be accomplished through improved population studies and better measures.

Most of the work on estimation and on service needs has focused on adults and there is a need for more work on this age group. For the working age population, more information is needed on the extent to which mental disorders are disabling with respect to work, family life, and community participation. For children and for individuals beyond 65 years, much more work is needed.

Some mental disorders, including dementia, are associated with aging. These disorders sometimes are included in mental health measures, and sometimes are included separately as age-related conditions. Mental disorders in aging, and how they are related to disability, warrant further study.

New measures of mental disorders in young children have been developed and provided the basis for estimates used in the Chartbook. Additional research is needed on treatment and prevention, and on the relationship between demographic and environmental factors and mental disorders and disability due to mental disorders in children. Much of the information on children comes from the schools, where the disorders may not be recognized or clearly described except in behavioral terms.

In particular, we found little information on youth between the ages of 16 and 22 years, when the first incidence of many serious disabling mental disorders, such as bipolar disorder and schizophrenia, often occurs. This group is not readily identified in school statistics and may never receive **special education** services.

Mental disorders obviously have a great impact on the Social Security Disability system and on employment services, where new enrollments have expanded over time. Our treatment systems as well as our service and employment systems appear inadequate to address the needs of the many people with disability due to mental disorders. More research is needed about the extent to which these people have access to appropriate services, and the extent to which service use affects employment and independent living outcomes.

More information is also needed on the relationship of the service system to the criminal justice system. There is considerable evidence from NIH studies and other studies conducted with parents and caregivers that lack of access to treatment and services can lead to institutionalization in juvenile or adult justice systems. How much of the identified need for prisons and correctional institutions is related to lack of knowledge and services in the mental health system?

Continued research supported by the National Institute on Disability and Rehabilitation Research, the National Institute of Mental Health and others can improve our understanding of how mental disorders are disabling, and which community systems are needed to reduce or eliminate barriers to full participation for people with mental disorders.

Glossary

This alphabetical list provides an explanation of terms that may require clarification. The definitions are taken from original surveys or cited publications as closely as possible, to convey the original authors' perspectives. Surveys that are mentioned in this Glossary are explained in more detail in the Appendix.

704 Report:. Annual Report of the Rehabilitation Services Administration's funded Independent Living Centers.

ADL: See **Activities of daily living (ADLs).**

Activities of daily living (ADLs): The **National Health Interview Survey (NHIS)** asks questions to identify people who "need the help of other persons with personal care needs such as eating, bathing, dressing or getting around...(inside the) home." (Adams & Marano, 1995). These particular activities are termed activities of daily living.

The **Survey of Income and Program Participation (SIPP)** definition of ADL includes eating, bathing, dressing or getting around inside the home, but also specifies getting into and out of bed or a chair, and toileting.

(See also **instrumental activities of daily living**.)

Activity limitation(s): On the **National Health Interview Survey (NHIS),** activity limitation refers to 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. (See **major activity** for an explanation of the activities associated with each age group.) People are classified into one of four categories: (1) unable to perform the major activity, (2) able to perform the major activity but limited in the kind or amount of this activity, (3) not limited in the major activity but limited in the kind or amount of other activities, and (4) not limited in any way. The NHIS classifies people as limited (groups 1-3) or not limited (group 4). People are not classified as limited in activity unless one or more chronic health conditions are reported as the cause of the activity limitation.

Census of State and Federal Adult Correctional Facilities. See Appendix for survey description.

Center for Mental Health Services (CMHS) Client Patient Sample Survey: See Appendix for survey description.

Children's Global Assessment Scale (CGAS) was used as a measure of functional impairment in the **MECA**. The CGAS score is chosen from a continuous scale ranging from 1 (extremely impaired) to 100 (doing very well). The CGAS score used was the lower of the two scores reported by the parents' interviewer and the youth interviewer.

Comorbidity is a technical term for having more than one condition or disorder at the same time.

Diagnostic and Statistical Manual (DSM-III, DSM-III-R and DSM-IV): The Diagnostic and Statistical Manual classifies and describes mental disorders and

their symptoms. Many current studies of mental illness and disability use DSM diagnoses to define the mental disorders.

Disabled worker: Under the Social Security definition, disabled workers are people under age 65 who receive benefits as part of the **Old Age, Survivors and Disability Insurance (OASDI)** program. They have been determined to be disabled under Social Security criteria (i.e., cannot engage in "substantial gainful activity.") They also have earned at least a certain minimum amount of wages in employment covered under Social Security in order to receive income from **Social Security Disability Insurance (SSDI).**

Disability: On the **NHIS**, disability refers to any long- or short-term reduction of a person's activity as a result of an acute or chronic condition.

On the 1997 **SIPP**, people age 15 and over were considered to have a disability if they met any of the following criteria: (1) used a wheelchair, a cane, crutches, or a walker; (2) had difficulty performing one or more **functional activities**; (3) had difficulty with one or more **activities of daily living (ADLs)**; (4) had difficulty with one or more **instrumental activities of daily living (IADLs).** Inclusion criteria related to mental disability were: (5) had one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer's disease, or some other type of mental or emotional condition) ; or (6) had any other mental or emotional conditions that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating or trouble coping with day-to-day stress. In addition, people were included who (7) had a condition that limited the ability to work around the house. A person also was considered to have a disability if (8) the person was 16 to 67 and had a condition that made it difficult to work at a job or business, or (9) received federal benefits based on an inability to work.

Disability due to a mental disorder is a general term used in this Chartbook to refer to limitations in functioning associated with a **mental disorder**. Related terms used by other researchers include **mental health disability, severe mental illness, serious mental illness**, and **mental disability**.

Disability program recipients defines people covered by Social Security Disability Insurance, Supplemental Security Income, Special Education or Early Intervention Services, and/or disability pensions.

Drop-out rate is used in the **IDEA** analysis. It is calculated by dividing the number of students age 14 and older who dropped out by the number of students age 14 and older who are known to have left school via graduating with a diploma, receiving a certificate of completion, reaching maximum age for services, died, or dropped out.

DSM, DSM-III, DSM-III-R, DSM-IV: An abbreviation for the **Diagnostic and Statistical Manual** and its versions. (see **Diagnostic and Statistical Manual**)

Emotional disturbance, as used in the **IDEA** data, means a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects a child's educational performance: (a) an inability to learn that cannot be explained by intellectual, sensory, or health

factors; (b) an inability to build or maintain satisfactory interpersonal relationships with peers and teachers; (c) inappropriate types of behavior or feelings under normal circumstances; (d) a general pervasive mood of unhappiness or depression; (e) a tendency to develop physical symptoms or fears associated with personal or school problems. Emotional disturbance also includes schizophrenia, but it does not apply to children who are socially maladjusted, unless it is determined that they have an emotional disturbance.

Epidemiologic Catchment Area (ECA) Survey: See Appendix for survey description.

Functional activity or activities: The **SIPP** asked respondents about their ability to perform the sensory and physical activities that include seeing, hearing, speaking, lifting/carrying, using stairs, walking, or grasping small objects. Difficulty in performing any of these functional activities is classified as a functional limitation in the SIPP.

The **NHIS-D** asked respondents about their ability to perform the following activities: (1) lift 10 pounds, (2) walk up 10 steps without resting, (3) walk a quarter of a mile, (4) stand for approximately 20 minutes, (5) bend down from a standing position, (6) reach up over the head or reach out, (7) use fingers to grasp or handle something and (8) hold a pen or pencil. Inability to perform any of these activities is classified as a functional limitation.

Functional disability: On the **NHIS-D**, functional disability includes: (1) limitations in or inability to perform a variety of physical activities; (2) serious sensory impairment; (3) serious symptoms of mental illness that severely interfered with life for the past year; (4) long-term care needs; (5) use of selected assistive devices; (6) developmental delays; (7) for children under age 5, inability to perform age-appropriate functions.

Functional limitation(s): See **functional activities** for definitions of specific physical activities that are used to define functional limitations. In the Colpe **NHIS-D** study of mental and emotional problems among children and youth, functional limitations were defined using four variables from Phase I of the NHIS-D:

- Does your child have *significant* problems at school with paying attention in class?
- Does your child have *significant* problems at school with controlling behavior?
- Does your child have *significant* problems at school with communicating with others?
- Because of a physical, mental, or emotional problem, does your child now have any difficulty playing or getting along with others his/her age? (The study controlled for the possibility that a child might have difficulty getting along with others because of a physical problem by including only those who had also been identified as having a mental or emotional problem.)

Graduation rate: Used in the **IDEA** analysis, the graduation rate is calculated as the number of students age 14 and older who graduated with a standard diploma divided by the number of students age 14 and older who are known to have left school via graduating with a diploma, receiving a certificate of completion, reaching maximum age for services, died, or dropped out.

IADL: See **Instrumental activities of daily living (IADLs).**

IDEA: IDEA stands for the Individuals with Disabilities Education Act, Part B Program. IDEA is now the major federal program that provides states with financial assistance to educate children and youth with disabilities. Before 1995, **special education** was also funded under ESEA.

IDEA includes children with mental retardation, hearing impairments including deafness, speech or language impairments, visual impairments including blindness, emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities. In order to qualify under IDEA, children must need **special education** and related services by reason of their disability.

ILCs/Independent Living Centers are consumer-controlled, community-based, cross-disability, nonresidential, private nonprofit agencies that are designed and operated within a local community by individuals with disabilities and provide an array of independent living services: information and referral, independent living skills training, peer counseling, and individual and systems advocacy. Most centers also are actively involved in one or more of the following activities: community planning and decision making; school-based peer counseling, role modeling, and skills training; working with local governments and employers to open and facilitate employment opportunities; interacting with local, state, and federal legislators; and staging recreational events that integrate individuals with disabilities with their non-disabled peers.

Many of the ILCs are supported with funds from the U.S. Rehabilitation Services Administration. The federally-funded Centers are required to report annually (the "**704 Report").** The national program started in 1978, and provide a model for the development of other centers.

Instrumental activities of daily living (IADLs): The **NHIS** collects information on people's needs for assistance from others in performing instrumental activities of daily living. The IADLs include: "doing everyday household chores, necessary business, shopping or getting around for other purposes." People who need assistance in **activities of daily living (ADLs)** were not asked about IADLs.

On the **SIPP**, instrumental activities of daily living include: going outside the home, keeping track of money or bills, preparing meals, doing light housework, taking prescription medicine in the right amount at the right time, and using the telephone.

(See also **activities of daily living**.)

Inventory of Local Jail Mental Health Services. See Appendix for survey description.

Inventory of Mental Health Services in Juvenile Justice Facilities. See Appendix for survey description.

Labor force participation rate (LFPR): The LFPR, which is the number of people in a given population that are in the labor force divided by the number of people in that population, is a primary measure in labor market analysis.

Major activity: In **NHIS**, people are classified in terms of the major activity usually associated with their particular age group. The major activities for the age groups are (1) ordinary play for children under 5 years of age, (2) attending school for those 5-17 years of age, (3) working or keeping house for people 18-69 years of age, and (4) the capacity for independent living (the ability to take care of personal needs such as eating and dressing, without the help of another person) for those 70 and over. People ages 18-69 years who are classified as keeping house are also classified according to their ability to work at a job or business. (See **activity limitation.**)

Major depressive disorder is characterized by abnormally depressed mood and marked loss of pleasure (not due to normal grieving) every day for at least two weeks. By definition, major depressive disorder causes clinically significant distress or impairment in social, occupational or other important areas of functioning. In the **National Comorbidity Survey Replication (NCS-R),** major depressive disorder was assessed using the Composite International Diagnostic Interview (CIDI) and the Structured Clinical Interview for DSM-IV.

MECA: The Methods for the Epidemiology of Child and Adolescent Mental Disorders. See Appendix for details.

Mental condition: The Survey on Income and Program Participation (SIPP) asks a number of questions designed to identify people who have a **mental disability**. Regarding conditions, the SIPP asks whether people have (1) a learning disability, (2) mental retardation, (3) Alzheimer's, senility or dementia, or (4) any other mental or emotional condition. The SIPP uses the term mental conditions to refer to these four specific conditions.

Mental disability is a term used by the U.S. Census and surveys done through the U.S. Census, like the Survey of Income and Program Participation (**SIPP**). In the SIPP, people were asked about specific mental conditions and symptoms and were classified as having a mental disability if they answered affirmatively to any of the conditions or symptoms.

Mental disorder is defined in the Report of the Surgeon General on Mental Health (U.S. Department of Health and Human Services, 1999) as a health condition characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning. We use the term mental disorder in the Chartbook to encompass a variety of related terms including **mental illness**, and **psychiatric disorder**. Not all mental disorders are disabling. When a person experiences limitations in functioning as a result of a mental condition, we use the term **disability due to a mental disorder.**

The term mental disorder also is used in specific surveys. In the **Epidemiologic Catchment Area (ECA)** studies, the presence of a mental disorder was

determined by asking about a person's symptoms, using the Diagnostic Interview Survey (DIS). People whose symptoms met the criteria for diagnosis based on the American Psychiatric Association's **Diagnostic and Statistical Manual (DSM-III or DSM-IIIR**) were classified as having a mental disorder. The term mental disorder is also used in the **National Comorbidity Study (NCS)** and the **Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA).**

Mental health: As defined in **Mental Health: Report of the Surgeon General**. (1999), "the successful performance of mental function, resulting in productive activities, fulfilling relationships with other people and the ability to adapt to change and to cope with adversity; from early childhood until late life, mental health is the springboard of thinking and communication skills, learning, emotional growth, resilience, and self-esteem. "

Mental health disability: A constructed measure using data from the core National Health Interview Survey (NHIS, 1994-95) and the National Health Interview Survey on Disability (NHIS-D, 1994-95). The measure includes: (1) having a limitation in any activity in any way due to a mental health problem (core questionnaire); (2) having any of 7 mental health symptoms that seriously interfere with day-to-day activities (working, going to school, or managing day-to-day activities); and (3) having any of these 7 symptoms or any of 9 mental health disorders that cause work disability (an inability to work or a limitation in the kind or amount of work a person can do).

The 7 mental health symptoms are:

(1) frequently depressed or anxious

(2) have a lot of trouble making and keeping friendships

(3) have a lot of trouble getting along with other people in social or recreational settings

(4) have a lot of trouble concentrating long enough to complete everyday tasks

(5) have serious difficulty coping with day-today stress

(6) frequently confused, disoriented, or forgetful

(7) have phobias or unreasonably strong fears, that is a fear of something or some situation where most people would not be afraid

The nine mental health disorders are:

(1) Schizophrenia

(2) Paranoid or delusional disorder, other than schizophrenia

(3) Manic episodes or manic depression, also called bipolar disorder

(4) Major depression (major depression is a depressed mood and loss of interest in almost all activities for at least 2 weeks)

(5) Antisocial personality, obsessive-compulsive personality, or any other severe personality disorder

(6) Alzheimer's disease or another type of senile disorder

(7) Alcohol abuse disorder

(8) Drug abuse disorder

(9) Other mental or emotional disorders that seriously interfered with ability to work, attend school, or manage day-today activities.

Mental illness: As defined in **Mental Health: Report of the Surgeon General**. (1999), "the term refers collectively to all mental disorders. Mental disorders are health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or "impaired functioning."

In some reports based on the **NHIS**, depression, anxiety, and other mental conditions are collectively described as mental illness.

The **Methods for the Epidemiology of Child and Adolescent Mental Disorders** MECA. See Appendix for details.

NCS: See **National Comorbidity Survey** in Appendix for survey description.

NCS-R: See **National Comorbidity Survey Replication** in Appendix for survey description.

NHIS: See **National Health Interview Survey** in Appendix for survey description.

NHIS-D: See **National Health Interview Survey on Disability** in Appendix for survey description.

NHIS-MH: See **National Health Interview Survey, Mental Health Supplement** in Appendix for survey description.

National Comorbidity Survey: See Appendix for survey description.

National Comorbidity Survey Replication: See Appendix for survey description.

National Health Interview Survey (NHIS): See Appendix for survey description.

National Health Interview Survey on Disability (NHIS-D): See **National Health Interview Survey on Disability** in Appendix for survey description.

National Health Interview Survey, Mental Health Supplement (NHIS-MH): See **National Health Interview Survey, Mental Health Supplement** in Appendix for survey description.

National Nursing Home Survey: See Appendix for survey description.

Non-institutionalized: Many estimates from federal surveys are based only on people who are not in institutions at the time of the survey, that is, the non-institutionalized people in the population. Institutions include correctional institutions, mental (psychiatric) hospitals, residential treatment centers, tuberculosis hospitals, chronic disease hospitals, homes for the aged, homes and schools for the mentally handicapped, homes and schools for the physically handicapped, homes for unwed mothers, homes for dependent and neglected

children, training schools for juvenile delinquents, and detention homes for juveniles.

OASDI: See Old Age, Survivors, and Disability Insurance.

Old Age, Survivors and Disability Insurance (OASDI): This federally-administered program provides monthly benefits to retired and disabled workers and their dependents and survivors. Benefits are earned in employment covered under Social Security. The part of OASDI that provides benefits to workers on the basis of disability is called **Social Security Disability Income (SSDI)**.

Perceived disability: In the **NHIS-D**, people were asked if they considered themselves to have a disability or are considered by others to have one. This reflects the definition of disability used in the Americans with Disabilities Act (ADA).

Personal assistance: In the **NHIS** core questionnaire, respondents are asked if they "need the help of other people" with personal care needs (**activities of daily living**) or handling other routine needs (**instrumental activities of daily living**). Those who answer affirmatively are categorized as needing personal assistance.

Prevalence: Prevalence is the number of cases of a disease, number of infected people, or number of people with a given attribute present during a particular interval of time. It is often expressed as a rate or percentage (for example, the prevalence of arthritis per 100 people during a year).

Psychiatric disorder: In the **National Comorbidity Survey**, respondents were interviewed about symptoms, using a structured diagnostic interview. Respondents whose symptoms met the criteria for a mental disorder as defined in the American Psychiatric Association's **Diagnostic and Statistical Manual**, Revised Third Edition (DSM-III-R) were classified as having a psychiatric disorder.

Rehabilitation Services Administration Program Data: See Appendix for description of data source.

Role impairment is a measure of disability due to major depressive disorder that was used in the **National Comorbidity Survey Replication (NCS-R**). Role impairment was a measure of the extent to which depression interfered with functioning in work, household, relationship, and social roles, and was assessed by scores on the Sheehan Disability Scale (SDS) and the World Health Organization disability assessment scale (WHO-DAS).

Serious mental illness (SMI): The term "serious mental illness" has been used to designate those individuals with conditions that are disabling. For instance, in the Alcohol, Drug, and Mental Health Administration (ADAMHA) Block Grant formula, 12-month prevalence rates for serious mental illness (SMI) was part of the funding measure. A committee of experts developed an operational definition of SMI. The measure was developed using the National Comorbidity Survey (NCS) and the Baltimore data from the Epidemiologic Catchment Area Study (ECA). The definition is based on disorder and functional impairment. The disorder measure was operationalized in the ECA by the DSM-III, and in the

NCS by a modified version of the DSM-III-R. Respondents were defined as having functional impairment if their disorder substantially interfered with vocational capacity, created serious interpersonal difficulties, was associated with a suicide plan or attempt at some time during the past 12 months, or if the disorder met criteria for **severe mental illness** as operationalized by NIMH (includes diagnoses of schizophrenia, schizo-affective disorder, manic depressive disorder, autism, severe forms of major depression, panic disorder, or obsessive compulsive disorder, because these disorders are so severe that they almost always lead to serious impairment if not treated).

In an earlier study, the 1989 Mental Health Supplement to the **National Health Interview Survey (NHIS-MH),** serious mental illness was defined as having one or more psychiatric disorders in the past year that interfered seriously with one or more aspects of daily life. Household respondents were asked whether anyone in the household had one of a number of psychiatric disabilities, which were listed by name.

Severe mental illness: In the **Epidemiologic Catchment Area (ECA)** studies, subjects were interviewed using the Diagnostic Interview Survey. In a study conducted by the National Center for Mental Health, the subjects were classified further as having a severe mental illness if their symptoms met the criteria for a particular set of **Diagnostic and Statistical Manual** (DSMIII) mental disorders and markedly interfered with social, occupational, and or school functioning. The diagnoses that met the criteria included schizophrenia and related disorders, manic-depressive (bipolar) disorder, autism and related disorders, as well as severe forms of major depression, panic disorder and obsessive compulsive disorder.

SIPP: See **Survey of Income and Program Participation** in the Appendix for survey description.

Social Security benefits: Social security benefits for individuals with disabilities include: (1) **Social Security Disability Insurance (SSDI),** which is a part of **the Old Age, Survivors and Disability Insurance (OASDI)** and (2) **Supplemental Security Income (SSI).** Individuals may receive benefits from either or both programs, depending on their work history, age, and financial resources. See individual listings under these terms for more information about each program.

Social Security Disability Insurance (SSDI): A federal program in the Social Security Administration providing monthly benefits to **disabled workers** and their dependents. A person builds protection through employment covered under Social Security (compulsory tax on earnings). The disability definition is an inability to engage in substantial gainful activity because of any medically determinable permanent physical or mental impairment. Later amendments required that the disability be of at least five months duration for a person to be eligible.

Social Security Program Data: See Appendix for description of data source.

Special education: Special education refers to free and appropriate public education and related services provided for children and youth with disabilities

from birth through age 21. Funding is provided via federal legislation IDEA, part B and, through 1995, by Chapter 1 of ESEA (SOP). (See also **IDEA).**

Supplemental Security Income (SSI): The federally-administered Supplemental Security Income program provides income support to people 65 and over, blind or disabled adults and blind or disabled children who have little or no income or other financial resources. In order to be considered disabled for SSI, an adult must be unable to engage in any substantial gainful activity by reason of a medically determinable physical or mental impairment that is expected to result in death or last for a continuous period of at least 12 months. Blindness is defined as 20/200 or less vision in the better eye with the use of correcting lenses, or with tunnel vision of 20 degrees or less. Children who have a physical or mental impairment that results in marked or severe functional limitations are eligible for SSI.

Survey of Program and Income Participation (SIPP): See Appendix for survey description.

Synthetic estimates: Synthetic estimates use statistical models to combine information from different data sources to estimate information that is not available from one source by itself.

U.S. Department of Education, Office of Special Education, Data Analysis System: See Appendix for description of data source.

Vocational Rehabilitation: This term refers to programs conducted by state Vocational Rehabilitation agencies. Vocational Rehabilitation (VR) programs provide or arrange for a wide array of training, educational, medical, and other services individualized to the needs of people with disabilities. The services are intended to help people with disabilities acquire, reacquire, and maintain gainful employment. The federal government provides most of the funding. Mental health conditions included in VR's data system include psychoses, neuroses, mental and emotional disorders, autism, traumatic brain injury (TBI), and other mental disorders.

With employment outcome: The successful placement of a **Vocational Rehabilitation** client into competitive, or self-employment for a minimum of 60 days after the completion of all necessary rehabilitation services. This category, "with employment outcome," was formerly called "rehabilitated."

Work disability: On the **NHIS-D**, work disability is defined as a limitation in or inability to work as a result of a physical, mental or emotional health condition.

Work limitation: On the **NHIS**, this category includes respondents with a chronic health condition that prevents the performance of work at all, allows only certain types of work to be performed or prevents regular working.

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Web site addresses

Web site addresses are subject to change. The Web sites listed in this Chartbook are current at the time of this document's preparation. This publication, **Chartbook on Mental Health and Disability in the United States**, is also available on the InfoUse Web site, which will be updated periodically:
http://www.infouse.com/disabilitydata/

Bureau of the Census:

SIPP: http://www.census.gov/hhes/www/disability/

Bureau of Justice Statistics:

http://www.ojp.usdoj.gov/bjs/

Centers for Disease Control and Prevention (CDC); National Center for Health Statistics

http://www.cdc.gov/nchs/

Disability Statistics Center (University of California, San Francisco):

http://www.dsc.ucsf.edu/

National Center for Education Statistics:

http://www.nces.ed.gov/

National Comorbidity Survey:

http://www.hcp.med.harvard.edu/ncs/

National Institute of Mental Health (NIMH):

http://www.nimh.nih.gov/

National Institute on Disability and Rehabilitation Research (NIDRR):

http://www.ed.gov/about/offices/list/osers/nidrr/

Office of Special Education Programs (OSEP):

http://www.ed.gov/ about/offices/list/osers/osep/

Social Security Administration (SSA):

http://www.ssa.gov/policy/

Substance Abuse and Mental Health Services Administration (SAMHSA):

http://www.mentalhealth.samhsa.gov/

U.S Surgeon General

http://www.surgeongeneral.gov/library/mentalhealth/home.html

Appendix

This appendix provides information on the sources of data used in this publication, and the limitations of each source.

The following summaries describe the surveys, their sampling formats, the size of the respondent bases, and definitions of terms used in the surveys, including how disability is measured. Information also is presented on databases that served as data sources for this publication. More details can be found in the original publications.

The **Census of State and Federal Adult Correctional Facilities** has been conducted six times since 1974. The data in this Chartbook are based on the 2000 Census of State and Federal Adult Correctional Facilities. The census collected data from 84 federal facilities, 1,295 state facilities, 22 facilities under both state and local authority, 3 facilities operated by the District of Columbia, and 264 privately operated institutions. The Bureau of Justice data reported in the Chartbook is based on information from the 1,558 public and private adult correctional facilities whose inmates were state prisoners. Locally operated jails and federal confinement facilities were not included in the reporting. In the report on state prisons, 1,121 prisons were classified as confinement facilities and 463 facilities were community-based. The census classified facilities as community-based if at least 50% of inmates regularly were permitted to leave unaccompanied. Community-based facilities included halfway houses, prerelease, work release and study release centers.

The Census of Correctional Facilities asked questions about the kinds of mental health services provided, and the percentage of inmates receiving those services. The census reports on these variables by gender, facility operation (private vs. public), authority to house (male vs. female), security level, facility size, and other characteristics of the facilities, as well as by state.

The **Center for Mental Health Services (CMHS) Client-Patient Sample Survey (CPSS)** was conducted in 1997. The survey sampled more than 8,000 youth in about 1,600 mental health care facilities, including clinics, hospitals, community centers and social service agencies. It is the first survey with a sample size large enough to allow researchers to calculate national estimates of children and youth who receive mental health services. The survey collected data on age, gender, race-ethnicity, living arrangement, family income, primary payment source, diagnoses and presenting problems.

The **Epidemiologic Catchment Area Survey (ECA)** was a multi-site, epidemiological and health services research study that assessed the prevalence and incidence of mental disorders, as well as use of mental health services. There were five sites for the study, and five universities that carried out the

research: New Haven, CT (Yale); Baltimore, MD (Johns Hopkins); St. Louis, MO (Washington University); Durham, NC (Duke); and Los Angeles, CA (UCLA).

Survey design and sampling -- Population sizes in the five sites ranged from 270,000 to 420,000 with different mixes of urban, rural and suburban locations as well as ethnic and age compositions. In each area, a probability sample of households was selected, and one adult, age 18 or over, was interviewed about the people in the household. The following groups were over-sampled: the elderly in New Haven and Durham, African-Americans in St. Louis, and Hispanic people in Los Angeles.

Respondents -- A total of 18,571 people were interviewed, with a range of 3,004 to 5,034 completed interviews at each site.

Definitions -- The ECA diagnosed **mental disorders** according to the diagnostic criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders – Third Edition (DSM-III) of the American Psychological Association.

The **Inventory of Local Jail Mental Health Services (1993)** was conducted by the Center for Mental Health Services in 1993. The survey was developed in conjunction with the American Jail Association, the National Sheriffs' Association, the American Correctional Association, the National Institute of Corrections, the Bureau of Justice Statistics (BJS) at the U.S. Department of Justice and other experts. In 1993, completed surveys were obtained from 3,076 of 3,191 identified facilities (96% response rate). Information was collected on types of mental health services, who provided the services, whether outside agencies also provided services, the volume of services and funding for the services. Data on mental health services were reported for the nation and by average daily population (ADP) of the jails.

The **Inventory of Mental Health Services in Juvenile Justice Facilities (1998)** was the first national survey on the availability of mental health services in the juvenile justice system. The survey was conducted by the Center for Mental Health Services, collecting data from 2,798 facilities in 1998. Of these, 1,022 were group homes and halfway houses, 673 were residential treatment facilities, 501 were detention centers, 269 were shelters, 162 were training schools, 139 were ranches, camps or farms, and 32 were diagnostic centers. The survey asked questions about the kinds of mental health services available to juveniles in the facilities, the professional disciplines of people providing services, the sources of funding and outside services provided. Data were reported in aggregate and by type of facility and type of service.

Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA). This survey was conducted in 1991-1992 through a cooperative agreement between NIMH and four Universities – Columbia, Emory, University of Puerto Rico, and Yale. The MECA was conducted in survey areas geographically convenient to the universities, chosen for diversity in socioeconomic characteristics, culture, and ethnicity. The study was designed to develop and test instruments and methods suitable for future large-scale epidemiologic studies of mental disorders among children and adolescents. Differences in sampling methods between sites prevented weighting of pooled

data, and proportions resulting from these un-weighted data are not representative of a larger population.

The target population was youth 9-17 years residing in housing units in the geographical area; institutionalized youth were not included. Both youth and adults respondents (parents) were required to speak English or Spanish as their primary language. The combined sample size for the four field sites was 1,285 youth-parent pairs.

National Comorbidity Survey (NCS): Mandated by Congress and conducted in 1990-92, the NCS was the first survey to administer a structured psychiatric interview to a nationally representative sample. The survey was designed to study the prevalence and correlates of **psychiatric disorders** and the use of services by people with those disorders. The study also focused on the **comorbidity** of substance use disorders and non-substance use psychiatric disorders.

Survey design, sampling , and respondents -- A household survey of over 8,000 respondents, ages 15 to 54 years, was conducted in 48 states, based on a stratified, multistage probability sample. The study also included other supplemental samples.

Definitions -- Psychiatric diagnoses were assigned based on a structured psychiatric interview (a modified version of the Composite International Diagnostic Interview, which provides diagnoses according to the Diagnostic and Statistical Manual of Mental Disorders – Third Edition, Revised, DSM-III-R, of the American Psychological Association). The study did not measure disability, but rather the presence or absence of psychiatric disorders.

The **National Comorbidity Survey Replication (NCS-R**) is a national survey of mental disorders, conducted in 2001-2002 as a follow-up to the **National Comorbidity Survey**. At the time of publication of this Chartbook, only data on major depressive disorder had been released from the NCS-R.

Survey design, sampling, and respondents -- A nationally representative face-to-face household survey of 9,090 respondents, 18 years and older, was conducted in 48 states, based on a stratified, multistage probability sample. The response rate was 73%. All respondents received a Part 1 diagnostic interview and 5,554 respondents received a Part 2 interview. The Part 1 sample was poststratified to match the 2000 Census population. Data on major depressive disorder were collected between February 2001 and December 2002.

Definitions – **Major depressive disorder** was assessed using the Composite International Diagnostic Interview (CIDI) and the Structured Clinical Interview for DSM-IV. **Role impairment** was a measure of the extent to which depression interfered with functioning in work, household, relationship, and social roles, and was assessed by scores on the Sheehan Disability Scale (SDS) and the World Health Organization disability assessment scale (WHO-DAS).

The **National Health Interview Survey (NHIS)** is a principal source of information on the health of the civilian **non-institutionalized** population of the United States. It has been conducted annually by the National Center for Health Statistics (NCHS) since 1957. Each year, the survey consists of a basic set of

questions on health, socioeconomic and demographic items as well as one or more special questionnaires to obtain more detailed information on major current health issues. A special questionnaire on mental health was conducted in 1989 and a special questionnaire on disability, the **NHIS-D**, was conducted in 1994-95. (See below for a description of these surveys.) The NHIS also provides information about **activity limitations** and chronic conditions.

Survey design and sampling -- The NHIS is conducted according to a multistage probability design, permitting continuous sampling of the civilian non-institutionalized population living in the United States. Each weekly sample is representative of the target population and is additive with other weekly samples. Sampling is done throughout the year, preventing seasonal bias. Information is obtained about health and other characteristics of each member of the household. The usual sample size is approximately 48,000 households or about 122,000 individuals each year.

Respondents -- The interviewed sample for 1994 was 116,179 individuals (45,705 households) and for 1995 was 102,467 individuals (39,239 households). Response rates were 94.1% in 1994, and 93.8% in 1995.

Definitions -- The NHIS defines chronic condition as one that has lasted for three months or more, or one that is on the NCHS list of chronic conditions regardless of onset. **Disability** refers to the state of being limited, due to a chronic mental or physical health condition, in the type or amount of activities. The NHIS has three measures of disability: (1) **activity limitation** in **major activity,** (2) **work limitation**, and (3) need for personal assistance with **activities of daily living (ADLs)**.

National Health Interview Survey on Disability (NHIS-D): In 1994-95, a special questionnaire on disability, the NHIS-D, was included as a topical module on the National Health Interview Survey. The survey was conducted in two phases. Phase I of the NHIS-D was designed to identify a wide range of children and adults with chronic conditions, impairments, disabilities and elevated service needs. Information was collected on 107,469 individuals, of whom 30,032 were children. The response rate for the NHIS-D, Phase I, was 87%. Phase II of the NHIS-D was designed as a follow-up questionnaire with individuals who were identified in Phase I. Data from Phase II were collected 1 year after each Phase I survey. Thus, the data collection period for the NHIS-D spanned from 1994-1996. Combined, data were collected on 205,560 persons, 41,100 of the sample were school-age children. See **functional activity** and **functional disability** in the Glossary for definitions of those terms as used in the NHIS-D.

National Health Interview Survey, Mental Health Supplement (NHIS-MH): In 1989, a special supplement on mental health was included as part of the NHIS. The purposes of the supplement were to update previous estimates of the prevalence of serious mental illness and to examine the use of mental health services and disability program participation of the population with serious mental illness. Information was collected on 113,231 people, a response rate of 96.8% of those who were interviewed on the basic NHIS questionnaire that year or 91.9% of the total NHIS sample for the year. Given that mental illness often carries great stigma and that the survey was not designed to diagnose mental

disorders, the data from this survey are likely to underestimate the actual prevalence of mental disorders.

The National Hospital Discharge Survey (NHDS) is a continuing nationwide survey of hospitals, focusing on short-stays rather than long-term care. On the basis of patient records, the survey estimates the causes of illness and injury nationwide.

Survey design and sampling -- Hospitals are selected to have patient records abstracted and analyzed. The survey uses a stratified sampling methodology, based on hospital size, number of discharges, primary diagnoses, patient age and gender group, and other factors. Statistical adjustments are made for non-responding hospitals and missing abstracts.

Respondents -- In 1995, 525 hospitals were selected, 512 met the inclusion criteria, 466 participated, and 263,000 medical records were abstracted.

Definitions -- Among other purposes, the survey provides national estimates on causes of short-term disabilities that result from illness and injury.

National Nursing Home Survey (NNHS): The National Center for Health Statistics has conducted six national nursing home surveys, beginning in 1973. The estimates in this publication of the number of elderly people in nursing homes were based on the results of the most recent (1999) NNHS.

Sampling -- The 1999 survey sampled nursing homes with 3 or more beds that routinely provided nursing care services. The sample of 1,423 homes was selected from a sampling frame of 18,000 nursing homes contained in the National Health Provider Inventory.

Sampling -- The survey used a stratified two-stage probability design. The first stage was a probability sample of nursing homes in the sampling frame. The first strata were bed size and certification status. Then homes were selected using systematic sampling with probability proportional to bed size. The second stage sampled up to six current residents an six discharges from each facility during a randomly selected designated month (between October 1, 1998 and September 30, 1999).

Data were collected in face-to-face interviews with nursing home staff via three questionnaires: The Facility Questionnaire, the Current Resident Questionnaire, and the Discharged Resident Questionnaire.

National Survey of Homeless Assistance Providers and Clients was done in 1996 to provide information about the providers of homeless assistance and the characteristics of homeless persons who use services based on a statistical sample of 76 metropolitan and non-metropolitan areas. The Census Bureau collected data for the survey between October 1995 and November 1996. Seventy six (76) geographic areas were included in the national sample. They were comprised of the 28 largest metropolitan areas, 24 randomly selected medium and small metropolitan areas, and another 24 randomly selected non-metropolitan areas (small cities and rural areas)

The national survey involved two phases. The first phase -- the "provider survey" -- was conducted from October 1995 through October 1996. It involved telephone interviews and a mail survey of assistance providers in the 76 geographic areas. Included were providers administering 16 categories of programs, including those that are specifically targeted to homeless people (e.g., shelters, soup kitchens, and outreach programs), as well as certain "mainstream" assistance programs that offer programs targeted to homeless persons.

The second phase -- the "client survey" -- was conducted over a four-week period in late October and early November 1996. It included interviews with a sample of approximately 4,000 persons who were using services in emergency shelters, soup kitchens, outreach programs, and other locations where assistance is provided.

Rehabilitation Services Administration Program Data are collected by the Rehabilitation Services Administration (RSA) from all the states and compiled annually. Information used in this Chartbook was made available by RSA from unpublished data analyses.

The **Survey of Income and Program Participation (SIPP)** is a multi-panel, longitudinal survey conducted by the U.S. Census Bureau. The SIPP covers the civilian, **non-institutionalized** population of residents living in the United States, and collects data on source and amount of income, labor force information, program participation and eligibility data, and general demographic characteristics. The SIPP also includes disability supplements that ask questions to determine individuals' disability status. Historical background and more detailed information on the SIPP can be found on the Internet at <http://www.sipp.census.gov/sipp/>.

Survey design and sampling -- The data in this publication are based on a number of overlapping waves and panels of the SIPP. The survey design is a continuous series of national panels in which the same households are interviewed every four months for periods ranging from 2 $^{1}/_{2}$ to 4 years. A cycle of four interviews covering the entire sample and using the same questionnaire is called a wave. Interviews are conducted by personal visit and by follow-up telephone calls. All household members who are 15 years and older are interviewed, if possible, and proxy response is permitted when individuals are not available for interviewing.

Respondents -- The data in this report come from the 1997 Americans with Disabilities study. It is based on data collected in wave 5 of the 1996 panel when approximately 32,000 households were interviewed. A rough estimate of the number of individuals interviewed per file would be 85,000 to 90,000, based on an estimated average of 2.5 individuals per household.

Definitions -- The questions that have been asked in the disability supplements of the SIPP were designed to be consistent with the definition of disability set forth in the Americans with Disabilities Act (ADA). People 15 years of age and older were considered to have a **disability** if they met any of the following criteria:

1) used a wheelchair, a cane, crutches or a walker;

2) had difficulty performing one or more **functional activities** (seeing, hearing, speaking, lifting/carrying, using stairs, walking, or grasping small objects;
3) had difficulty with one or more **activities of daily living (ADLs),** which include getting around inside the home, getting in and out of bed or a chair, bathing, dressing, eating or toileting;
4) had difficulty with one or more **instrumental activities of daily living (IADLs),** which include going outside the home, keeping track of money and bills, preparing meals, doing light housework, taking prescription medicines in the right amount at the right time, or using the telephone;
5) had one or more specified conditions (a learning disability, mental retardation or another developmental disability , Alzheimer's disease, or some other type of mental or emotional condition);
6) had any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day-to-day stress);
7) had a condition that limited the ability to work around the house;
8) if age 16-67, had a condition that made it difficult to work at a job or business;
9) received federal benefits based on an inability to work.

Individuals were considered to have a severe disability if they met criteria #1, 6, or 9; or had Alzheimer's disease, or mental retardation or another developmental disability; or were unable to perform one or more of the activities in criteria #2,3,4,7, or 8.

Social Security Administration Program Data is collected by the Social Security Administration (SSA) and published each year in the Annual Statistical Supplement to the Social Security Bulletin. A substantial number of the tables in this publication are based on sampling one-percent or ten-percent of the files from the administrative records. Due to sampling error, some of these estimates may be different from the results that would have been obtained if all the records had been used. Detailed information on sampling variability may be obtained in the Annual Supplement. [See also the Glossary for definitions of the following terms that are used in the Social Security Administration Program Data: **Disabled worker; Old Age, Survivors and Disability Insurance (OASDI); Social Security benefits; Social Security Disability Insurance (SSDI)**; and **Supplemental Security Income (SSI).**]

U.S. Department of Education, Office of Special Education Programs, Data Analysis System: This data system is the source of program data on special education in the United States. Data is collected from all the states on children and youth, ages 0 to 21 years, who are served under **IDEA**, the Individuals with Disabilities Education Act. Analyses of these program data are published each year in an annual report to Congress.

The **Youth Risk Behavior Survey**, conducted every two years by the Centers for Disease Control, is a nationally representative survey of public and private high

school students, grades 9-12. The survey monitors priority health risk behaviors that contribute to the leading causes of death, disability and social problems among youth in the United States. A three-stage sampling frame, including an oversampling of black and Hispanic students, yielded 13,601 usable questionnaires from 150 schools in 2001. The school response rate was 75% and the student response rate was 83%, resulting in an overall response rate of 63%. Student participation was anonymous and voluntary. Students completed the self-administered questionnaire and recorded their responses directly onto a computer-scannable booklet or answer sheet. The data was weighted and analyzed using SUDAAN.

Facts sheet on mental disorders: key facts, depression, dementia, helath and support and WHO response.Â The burden of mental disorders continues to grow with significant impacts on health and major social, human rights and economic consequences in all countries of the world. Depression. Depression is a common mental disorder and one of the main causes of disability worldwide. Globally, an estimated 300 million people are affected by depression.Â Developmental disorder is an umbrella term covering intellectual disability and pervasive developmental disorders including autism. Developmental disorders usually have a childhood onset but tend to persist into adulthood, causing impairment or delay in functions related to the central nervous system maturation.