Report to the President from the President's Commission on Mental Health, 1978.

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The President's Commission on Mental Health

1978

Volume I

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The President's Commission on Mental Health

The Commission was established by Executive Order No. 11973, signed by President Carter February 17, 1977, to review the mental health needs of the Nation and to make recommendations to the President as to how the Nation might best meet these needs.

The Commission held public hearings across the country, and received the assistance of hundreds of individuals who comprised special fact-finding task panels.

These task panels, made up of the Nation's foremost mental health authorities and other volunteers interested in mental health, produced and submitted to the Commission the reports which are contained in the Appendices to the Commission's Report.

The Report to the President from the President's Commission on Mental Health consists of four volumes:

Volume I contains the Commission's Report and Recommendations to the President.

Volumes II, III, and IV are Appendices to the Report. These contain the reports of task panels comprised of approximately 450 individuals from throughout the country who volunteered their expertise, perceptions, and assessments of the Nation's mental health needs and resources in specific categories.

Although the Commission has adopted certain of the options proposed by the task panels, the opinions and recommendations contained in the panel reports should be viewed as those of the panel members; they do not necessarily reflect the views of the Commission. Rather, their publication is intended to share with the public the valuable information these individuals so generously contributed to the Commission.

The President's Commission on Mental Health

Rosalynn Carter, Honorary Chairperson

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Ruth B. Love, Vice-Chairperson
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Charles V. Willie

Acknowledgments

The work of the President's Commission on Mental Health could not have been accomplished without the voluntary contributions made by hundreds of individuals who served on various task panels created to provide data, information, and expertise. The Commission is grateful for their invaluable assistance.

We also wish to acknowledge the contributions made by hundreds of others who comprised working groups or who individually assisted the task panels in their work.

Testimony, both written and oral, given by many throughout the country at regional public hearings of the Commission was of great importance as we began our task, and to each person who took the trouble to prepare such testimony go our special thanks.

The willing and full cooperation of many congressional committees, governmental agencies, both Federal and State, which provided needed information and advice, notably the Alcohol, Drug Abuse, and Mental Health Administration, the National Institute of Mental Health and other agencies of the Department of Health, Education, and Welfare, and the Department of Housing and Urban Development deserves special recognition. The Secretary of the Department of Health, Education, and Welfare has been particularly supportive by making funds and staff available to the Commission during this year.

The Institute of Medicine of the National Academy of Sciences undertook a series of special studies at the request of the Commission. While the reports of these studies will be published by the Institute, we wish to express our particular appreciation for them.

To the hundreds of public and private professional and citizen organizations who gave us the benefit of their expertise, as well as the thousands of citizens and their families who shared with us their personal experiences keeping us always mindful of the individual whose life has been affected by mental or emotional disability, our grateful thanks.

Last, we wish to give special thanks to the dedicated and highly professional staff of the Commission, the unstinting contributions of the support staff, and the help of the many volunteers who so generously assisted them.

All contributions mentioned above are identified, insofar as possible, at the back of the volume or in the Appendices.

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THE WHITE HOUSE

WASHINGTON

The President
The White House
Washington, D.C.

Dear Mr. President:

We present for your consideration the Final Report of the President's Commission on Mental Health.

The one-year study we undertook at your direction has convinced us that a substantial number of Americans do not have access to mental health care of high quality and at reasonable cost. For many, this is because of where they live; for others, it is because of who they are—their race, age, or sex; for still others, it is because of their particular disability or economic circumstances.

Mental health services in this country are located predominantly in urban areas. For those who live in rural areas, small towns, and many of the poorer sections of the Nation's cities, specialized mental health facilities and personnel are frequently nonexistent, and the services available are rarely comprehensive.

For many members of America's ethnic and racial minority populations, the mental health personnel and services that are available are either inadequate or fail to take into account their different cultural traditions.

Many children, adolescents, and older Americans do not have sufficient access to services or to personnel trained to respond to the special needs which are characteristic of their ages.

While not enough is known about the causes and treatment of chronic mental illness, we do know that thousands who are so disabled receive deplorably inadequate assistance.

Our study has also convinced us that, for the long run, the Nation will need to devote greater human and fiscal resources to mental health. We now devote only 12 percent of general health expenditures to mental health. This is not commensurate with the magnitude of mental health problems and does not address the interdependent nature of physical and mental health. We must begin now to seek a realistic allocation of resources which reflects this interdependence.

Further, since over half the dollars for mental health care are still spent in large State institutions and mental health-related nursing homes, there is an urgent need for a national policy that will alter the current balance of mental health expenditures in order to develop needed community-based services.

Despite shortcomings and inequities, the foundation exists for reaching the goal of making high quality public and private mental health services available at reasonable cost to all who need them. To bring us nearer this goal, during the next decade we must:

- —Develop networks of high quality, comprehensive mental health services throughout the country which are sufficiently flexible to respond to changing circumstances and to the diverse racial and cultural backgrounds of individuals. Wherever possible these services should be in local communities.
- —Adequately finance mental health services with public and private funds so that care is available at reasonable cost.
- —Assure that appropriately trained mental health personnel will be available where they are needed.
- —Make available where and when they are needed services and personnel for populations with special needs, such as children, adolescents, and the elderly.
- —Establish a national priority to meet the needs of people with chronic mental illness.
- —Coordinate mental health services more closely with each other, with general health and other human services, and with those personal and social support systems that strengthen our neighborhoods and communities.
- —Broaden the base of knowledge about the nature and treatment of mental disabilities.
- —Undertake a concerted national effort to prevent mental disabilities.
- —Assure that mental health services and programs operate within basic principles protecting human rights and guaranteeing freedom of choice.

To achieve these objectives, we cannot rely solely on the Federal Government. We must have a strategy developed and implemented by partners—the private sector with the public sector, the Federal Government with State and local governments, those working in mental health with those working in general health and related services. In these new arrangements we must define more clearly areas of responsibility and accountability.

In this year, we have come to a much deeper appreciation of the complexities of mental health and mental illness. Because each involves complicated interactions among so many diverse factors, society's perceptions of them are constantly changing.

We believe our recommended goals and directions are sound for now. They can serve as guides to progress over the next few years. But many of the issues we have addressed will themselves change over time. New knowledge will broaden understanding and may necessarily lead to different approaches.

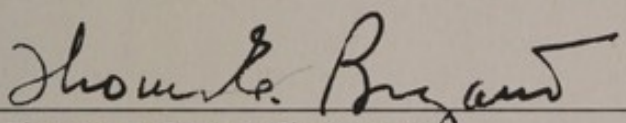
With the submission of this Report, we complete our work.

We wish to thank you for this opportunity and for your support. We wish to express our particular appreciation to our Honorary Chairperson, Rosalynn Carter. Her dedication to improving care for those in need has given us forceful leadership

and sparked a spirit of excitement and hope around the country. For this, all who have been affected by mental health problems and all who work in this field are grateful.

Respectfully,

The President's Commission on Mental Health,

by 

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Mental Health In America: 1978

Mental Health in America: 1978

Introduction

In the United States today, mental health care of high quality and reasonable cost should be readily available to all who need it.

This is not the case.

We are impressed with the progress that has been made in this direction. We are equally impressed by what has not occurred.

The mental health services system which currently exists is still in a state of evolution. It combines public and private personnel, facilities, and financing without clearly established lines of responsibility or accountability.

For some Americans this system presents few problems. They are able to obtain the care they need.

For too many Americans this does not occur. Despite improvements in the system, there are millions who remain unserved, underserved, or inappropriately served.

—Because of where they live or because of financial barriers, far too many Americans have no access to mental health care.

—Because the services available to them are limited or not sufficiently responsive to their individual circumstances, far too many Americans do not receive the kind of care they need.

—Because of their age, sex, race, cultural background, or the nature of their disability, far too many Americans do not have access to personnel trained to respond to their special needs.

In the pages that follow, we present our findings and recommendations for dealing with these and other problems we have observed and encountered. Because we are a public commission, we have concentrated our attention primarily on publicly funded mental health efforts. Many of our proposed solutions to problems have implications for private mental health practitioners and for private mental health institutions.

Findings and Assessment

Within the past quarter of a century a number of significant developments have shaped America's response to the needs of those with mental and emotional problems.

—Basic research in America and abroad following World War II contributed to the development of more effective psychoactive drugs and forms of psychotherapy, each of which made possible the release of thousands of patients from large mental institutions.

—The final report of the Joint Commission on Mental Illness and Health, published in 1961, placed strong emphasis on community-based services by calling for a reduction in size and, where appropriate, the closing of large State hospitals; the development of mental health services in local communities; and the upgrading of quality of care in remaining smaller State hospitals so that patients could be returned as quickly as possible to their communities.

—The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963, plus subsequent amendments, provided the programmatic vehicle for establishing a network of publicly funded community mental health centers throughout the country.

—Major investments by the Federal Government in training mental health professionals and a dramatic rise in the number and types of mental health personnel, including paraprofessionals, have resulted in a marked increase in mental health care providers in both the public and private sectors.

—Federal initiatives in health care financing programs, such as Medicare and Medicaid, and an expansion of benefits in social service programs have in some States enabled a larger number of people with mental disabilities to live in their own communities instead of State hospitals.

—A Joint Commission on the Mental Health of Children was established in 1965 to address the problems of inadequate mental health services for children and adolescents. Even though many of its recommendations were not acted upon, some resulted in additional services for children and adolescents.

—The civil rights and consumer movements have been the impetus for legislative and court activities which have accelerated the release of patients from large mental institutions.

—Reforms of State laws have led to changes in commitment procedures, and court decisions emphasizing patients' rights have set minimum standards for patient care in institutions.

Before these developments occurred, large, generally isolated, State mental hospitals were the mainstay of America's publicly funded mental health services system; approximately 75 percent of all the people who received care were residents of the institutions in which they received that care. Now three of every four persons receiving formal mental health care are outpatients in public and private settings. More inpatient care in public and private facilities is also available in local communities. While the number of people in State hospitals has declined from more than 550,000 in 1955 to less than 200,000 in 1975, State hospitals continue to provide a major portion of long-term care for those with chronic mental illness.

An increase in the numbers and types of mental health personnel and in the range of services they provide has accompanied this shift in the location of mental health services.

The supply of psychiatrists, psychologists, psychiatric social workers, and psychiatric nurses has more than doubled. They have found employment not only in hospitals, clinics, and other mental health facilities, public and private, but also in such diverse settings as courts, correctional institutions, and schools.

Many other categories of professional and paraprofessional mental health workers now are involved in providing care. These include marriage, sex, and family therapists; counseling and guidance personnel; recreational, art, music, drama, dance, and vocational therapists; and alcoholism and drug abuse counselors. Paraprofessionals comprise almost half the patient care staff of mental health facilities.

Beyond this, many people whose work is not primarily in the mental health area, such as primary care physicians, clergy, teachers, and public health nurses, are actively engaged in helping people with mental and emotional difficulties.

The dollars devoted to providing mental health services have also increased markedly. In the late 1950's the direct cost of mental illness was estimated to be $1.7 billion a year. By 1976 the direct costs of providing mental health services was about $17 billion, approximately 12 percent of all health costs. Over 50 percent of these expenditures were for services provided in nursing homes and public mental hospitals.

The Underserved

Despite progress, many persons who should have benefited from these changes still receive inadequate care. This is especially true of people with chronic mental illness, of children, adolescents, and older Americans.

Racial and ethnic minorities, the urban poor, and migrant and seasonal farmworkers continue to be underserved.

In rural America there are few facilities and few people trained to provide mental health care.

Changes in public attitudes have led to an awareness of the lack of appropriate services for many women and for such groups as Vietnam veterans, the deaf, and others with physical handicaps.

By concentrating on the difficulties these Americans experience in obtaining care, we can see more clearly the fundamental problems in planning, organizing, delivering, and financing mental health services throughout the mental health system.

The plight of the chronically mentally ill illustrates the difficulties that exist in developing comprehensive service systems in local communities. There are people

who have severe mental disabilities which often persist throughout their lives. Some require a sheltered environment, some need a variety of services, and some need only periodic assistance. There are still other chronically disabled individuals who achieve a high level of independent functioning. As a group they are the individuals who are, have been, or in earlier times might have been residents of State mental hospitals and who were intended to benefit most from the shift to community-based care.

A basic premise of the movement toward community-based services was that care would be provided in halfway houses, family and group homes, private hospitals and offices, residential centers, foster care settings, and community mental health centers. Social and human services were to have been integrated with more formal mental health care, resulting in a complete range of services.

In the few communities that had this broad range of services, many patients made effective transitions from State hospitals to the community. The majority of communities, however, did not have the necessary services, were not given proper assistance to develop them, or enough time to prepare to receive returning patients.

Time and again we have learned—from testimony, from inquiries, and from the reports of special task panels—of people with chronic mental disabilities who have been released from hospitals but who do not have the basic necessities of life. They lack adequate food, clothing, or shelter. We have heard of woefully inadequate follow-up mental health and general medical care. And we have seen evidence that half the people released from large mental hospitals are being readmitted within a year of discharge. While not every individual can be treated within the community, many of the readmissions to State hospitals could have been avoided if comprehensive assistance had existed within their communities.

Because sufficient services and appropriate financial assistance are not available, many people with chronic mental illness have no choice but to live in poorly maintained boarding homes or cheap occupancy hotels and rooming houses. Because public and private health insurance programs provide insufficient outpatient benefits, many, both young and old, who could be cared for in community settings end up in nursing homes, which often are not equipped to serve patients with mental health needs.

These needs cannot be met unless we make basic changes in public policies and programs, particularly in how we plan, coordinate, and finance mental health care. There must be a much clearer delineation of responsibility and accountability for the care delivered to this population.

It makes little sense to speak about American society as pluralistic and culturally diverse, or to urge the development of mental health services that respect and respond to that diversity, unless we focus attention on the special status of the groups which account for the diversity, whether defined in terms of race, ethnicity, sex, age, or disability.

According to the 1975 Special Census, the population of America includes 22 million Black Americans and 12 million Hispanic Americans. There are 3 million Asian and Pacific Island Americans and 1 million American Indians and Alaska Natives. Appropriate services are not available to many of them, even though social, economic, and environmental factors render them particularly vulnerable to acute and prolonged psychological and emotional distress.

Too often, services which are available are not in accord with their cultural and linguistic traditions. The number of Asian and Pacific Island Americans utilizing

mental health services increases dramatically when services take into account their cultural traditions and patterns. Language barriers prevent many Hispanic Americans from seeking care, and when they do seek it the absence of bilingual personnel can reduce the effectiveness of treatment. Government funded or operated programs often ignore existing cultural, social, and community supports in the American Indian community.

A frequent and vigorous complaint of minority people who need care is that they often feel abused, intimidated, and harassed by non-minority personnel. Like everyone else, minorities feel more comfortable and secure when care is provided by practitioners who come from similar backgrounds. Yet fewer than 2 percent of all psychiatrists in America are Black. The percentage of Hispanic American psychiatrists is even lower, and there are only 13 psychiatrists in the country who are American Indian. A recent survey by the American Psychological Association estimates that of all the doctoral-level health services providers in psychology, 0.9 percent are Black, 0.7 percent are Asian, 0.4 percent are Hispanic, and 0.1 percent are American Indian.

Seasonal and migrant farmworkers and their families, many of whom belong to racial minorities, represent a population of approximately five million which has been almost completely excluded from mental health care. The constant mobility as they move from place to place in search of work frequently prevents them from obtaining any care, let alone continuity of care.

The common bond among these racial and ethnic minority groups is that all encompass people whose basic mental health needs have not been sufficiently understood by those involved in the planning and delivery of mental health services.

Just as there are special mental health needs that relate to cultural and racial diversity, there are special needs that relate to age.

Our laws and public policies affirm the principle that every American child should have the opportunity to realize his or her full potential. Appropriate mental health care can be essential for the realization of this potential.

As the Commission traveled throughout America, we saw and heard about too many children and adolescents who suffered from neglect, indifference, and abuse, and for whom appropriate mental health care was inadequate or nonexistent. Too many American children grow to adulthood with mental disabilities which could have been addressed more effectively earlier in their lives through appropriate prenatal, infant, and early child development care programs.

Troubled children and adolescents, particularly if they are from racial minorities, are too often placed in foster homes, special schools, mental and correctional institutions without adequate prior evaluation or subsequent follow-up. Good residential facilities specializing in the treatment of special problems are in short supply.

During the past two decades, many adolescents have struggled to adapt to rapid social changes and conflicting, often ambiguous, social values. There has been a dramatic increase in the use and misuse of psychoactive drugs, including alcohol, among young people and nearly a three-fold increase in the suicide rate of adolescents.

Services that reflect the unique needs of children and adolescents are frequently unavailable. Our existing mental health services system contains too few mental health professionals and other personnel trained to meet the special needs of children and adolescents. Even when identified, children's needs are too often

isolated into distinct categories, each to be addressed separately by a different specialist. Shuttling children from service to service, each with its own label, adds to their confusion, increases their despair, and sets the pattern for adult disability.

At the other end of the age spectrum, the 23 million Americans over the age of sixty-five—one-third of whom are below the official poverty line—constitute another large segment of the population underserved by our current mental health care system.

The prevalence of mental illness and emotional distress is higher among those over age sixty-five than in the general population. Up to 25 percent of older persons have been estimated to have significant mental health problems. Yet only 4 percent of patients seen in public outpatient mental health clinics and 2 percent of those seen in private psychiatric care are elderly.

Part of the problem is attitudinal. Too often the elderly are told, and many believe, that adverse psychological symptoms are natural aspects of growing old. Senility is a term loosely applied to thousands of older Americans, yet as many as 20 to 30 percent of those so labeled have specific conditions that can be diagnosed, treated, and often reversed.

The elderly are subjected to multiple psychological stresses brought about by such things as social isolation, grief over loss of loved ones, and fears of illness and death. Yet there are almost no outreach efforts or in-home services in existing mental health programs to bring them into contact with the kinds of services they need. The personnel who are available to help them are often inadequately trained to address their special concerns. Instead, we confine our older citizens to nursing homes where good mental health care is seldom available.

Most of the problems we have described are expressed in terms of the needs of special segments of the population. They refer to individuals who do not receive adequate mental health care because of who they are.

This is also true for women. Many do not receive appropriate care from the mental health service system. The rapidly changing role of women has left many traditionally trained mental health practitioners ill-prepared to deal with the new problems that women face as a result. We know that women have expressed realistic concerns about the quality of their lives and their place in our society. Many report that the response of the mental health services system is often "treatment" aimed at encouraging them to accept the status quo and their "natural" position in life. We are concerned by the failure of mental health practitioners to recognize, understand, and empathize with the feelings of powerlessness, alienation, and frustration expressed by many women.

Other Americans do not receive adequate care because of where they are. While this is particularly true of those who live in rural America, it is also true of Americans who live in small towns and in the poorer sections of American cities.

Mental health personnel and facilities, particularly those in the private sector, are located primarily in the more affluent urban areas of the country. Americans who do not live in these areas do not have ready access to mental health services. They often must travel long distances even to receive emergency care, and neither specialized nor comprehensive services are available to them.

Defining Mental Health Problems

Documenting the total number of people who have mental health problems, the kinds they have, how they are treated, and the associated financial costs is

difficult, not only because opinions vary on how mental health and mental illness should be defined, but also because the available data are often inadequate or misleading. This difficulty is compounded by the subjective nature of many mental health problems. People fear mental illness and they often do not report it. Many problems are never treated and never recorded.

For the past few years the most commonly used estimate has been that, at any one time, 10 percent of the population needs some form of mental health services. This estimate has been used in national projections for the services and personnel needed to provide mental health care. There is new evidence that this figure may be nearer 15 percent of the population.[1]

While these figures depict the magnitude of this Nation's mental health problems, they tell us little about the specific nature of these problems. They also tell us little about the types of mental health services required to meet these problems.

We know that 6.7 million people, 3 percent of the American population, were seen in the specialized mental health sector in 1975. Approximately 1.5 million persons were hospitalized in the specialized mental health sector in 1975.

We also know that, of the estimated 2 million Americans who have been or would be diagnosed as schizophrenic, approximately 600,000 receive active treatment in any one year. Most current estimates state that about 1 percent of the population suffers from profound depressive disorders. There is new evidence that this figure may be higher.[2] More than 1 million Americans have organic psychoses of toxic or neurologic origin or permanently disabling mental conditions of varying causes.

Because diagnostic criteria vary so widely, different surveys of general populations show that the overall prevalence of persistent, handicapping mental health problems among children aged three to fifteen ranges from 5 to 15 percent. These conditions include emotional disorders, the so-called conduct disorders, and impairments or delays in psychological development.

As many as 25 percent of the population are estimated to suffer from mild to moderate depression, anxiety, and other indicators of emotional disorder at any given time. The extent and composition of this group varies over time. Although most of these problems do not constitute mental disorders as conventionally diagnosed, many of these persons suffer intensely and seek assistance. By and large, such individuals cope with these stresses with the aid of family, friends, or professionals outside the mental health system. These individuals constitute a significant portion of primary health care practice in the United States.

There are large numbers of Americans who suffer from serious emotional problems which are associated with other conditions or circumstances:

—Alcohol abuse is a major social, physical, and mental health problem with an annual cost to the Nation estimated at over $40 billion. Approximately 10 million Americans report recent alcohol-related problems, yet only 1 million are receiving treatment for alcoholism. While many are treated in mental hospitals, outpatient treatment for alcoholism has in recent years been increasingly independent of the mental illness treatment network.

—The non-medical use and misuse of psychoactive drugs is a complex phenomenon which is not well understood. It has social, legal, health, and mental health implications. Many with drug-related problems turn to mental health practitioners and facilities for assistance. As in the case of alcoholism, most treatment efforts are independent of the mental health service system.

—There were an estimated 200,000 cases of child abuse reported in America in 1976. Because many cases are never reported, the actual number is much larger. This is an enormous, poorly understood problem with serious mental health implications.

—By conservative estimates at least 2 million American children have severe learning disabilities which, if neglected, can have profound mental health consequences for the child and the family.

—There are 40 million physically handicapped Americans, many of whom suffer serious emotional consequences because of their disabilities.

—According to the President's Committee on Mental Retardation, one-third of the 6 million people who are mentally retarded suffer from multiple handicaps, which often include serious emotional difficulties.

America's mental health problems cannot be defined only in terms of disabling mental illnesses and identified psychiatric disorders. They must include the damage to mental health associated with unrelenting poverty and unemployment and the institutionalized discrimination that occurs on the basis of race, sex, class, age, and mental or physical handicaps. They must also include conditions that involve emotional and psychological distress which do not fit conventional categories of classification or service.

Our purpose in emphasizing this broad view of mental health is not to foster unrealistic expectations about what formal mental health services can or should accomplish. It is not to suggest those working in the mental health field can resolve far-reaching social issues. We are firmly convinced, however, that mental health services cannot adequately respond to the needs of the citizens of this country unless those involved in the planning, organization, and delivery of those services fully recognize the harmful effect that a variety of social, environmental, physical, psychological, and biological factors can have on the ability of individuals to function in society, develop a sense of their own worth, and maintain a strong and purposeful self-image.

National Goals

To meet the needs of Americans with mental health problems we must affirm the goal that high quality mental health care should be available to all who need it at reasonable cost.

This goal will not be reached quickly. It will require a concerted national effort. We will have to devote greater human and fiscal resources to mental health. There must be a more realistic balance in the allocation of resources between physical health and mental health. Only 12 percent of this Nation's general health care expenditures are for mental health services. This is hardly commensurate with the magnitude of mental health problems facing the Nation.

During the next decade we must take steps to:

—Develop networks of high quality, comprehensive mental health services throughout the country which are sufficiently flexible to respond to changing circumstances and to the diverse racial and cultural backgrounds of individuals. Wherever possible these services should be in local communities.

—Adequately finance mental health services with public and private funds.

—Assure that appropriately trained mental health personnel will be available where they are needed.

—Make available where and when they are needed services and personnel for populations with special needs, such as children, adolescents, and the elderly.

—Establish a national priority to meet the needs of people with chronic mental illness.

—Coordinate mental health services more closely with each other, with general health and other human services, and with those personal and social support systems that strengthen our neighborhoods and communities.

—Broaden the base of knowledge about the nature and treatment of mental disabilities.

—Undertake a concerted national effort to prevent mental disabilities.

—Assure that mental health services and programs operate within basic principles protecting human rights and guaranteeing freedom of choice.

While we will recommend changes in how we plan and deliver mental health services, how we develop needed manpower, and how we finance care, it is clear that in the long run we will need a greater knowledge base both to improve care and to undertake a concerted national effort in preventing mental disabilities.

The scientific advances in basic and applied research which have resulted in greater understanding and more effective therapeutic approaches in mental health came as a result of a national research capacity which was organized and sustained in large measure by Federal investments. In recent years this investment has been decreasing, and our research capacity has now eroded to the point at which both the quality and breadth of mental health research are in serious danger. We must know more about the underlying causes of mental illness, mental retardation, alcoholism, drug dependence, child abuse, and learning disabilities. We must know more about the efficacy of different treatments and different preventive strategies and approaches.

New knowledge is of particular importance for prevention. In our review we have found that preventive efforts receive insufficient attention at the Federal, State, and local levels. Not only is there no national strategy for prevention, there is no concerted effort to assess what is already known and to evaluate the effectiveness of promising approaches.

Finally, the personal and social supports which currently exist in our neighborhoods and communities are one of the great resources in American society for maintaining mental health and for preventing the development of serious mental and emotional disabilities. Families, friends, neighbors, schools, religious institutions, self-help groups, and voluntary associations are the individuals and kinds of organizations to which most of us initially turn when we have problems. Without impairing the autonomy, natural strengths, and effectiveness of these supports, we need to enhance their ability to contribute to the mental health of friends, neighbors, and families. In this way we may greatly improve the Nation's capability of preventing mental disability and of providing necessary care.

Recommendations

Recommendations

Introduction

In assessing mental health care in 1978 we have been struck by the inconsistencies that exist between what we know should be done and what we do. We know that services should be tailored to the needs of people in different communities and circumstances, but we do not provide the choices that make this possible. We know that people should seek care when they need it, but we do little to change the public attitudes that often keep people from seeking help. We know that people are usually better off when care is provided in settings that are near families, friends, and supportive social networks, yet we still channel the bulk of our mental health dollars to nursing homes and State mental hospitals.

The recommendations that follow focus on eight areas we consider of major importance. Annotations are provided which expand upon the material presented, describe methods of implementing certain recommendations, and present additional recommendations.

This Commission realizes that we cannot rely solely on the Federal Government to solve these problems. We must have a strategy developed and implemented by partners—the private sector with the public sector, the Federal Government with State and local governments, those working in mental health with those working in general health and related human services. This thought has guided us in developing our recommendations.

In addition to the problems we address in the Report, there are three mental health-related areas to which we wish to call special attention: alcohol-related problems, the misuse of psychoactive drugs, and mental retardation.

The misuses of alcohol and psychoactive drugs in contemporary America are exceedingly complex phenomena with serious social, health, and mental health aspects. The Commission has recommended increased research in both areas.

In the case of alcohol-related problems, we believe it is urgent that we develop a national plan of action. As a first step, the Commission recommends the creation of a broadly representative national group to analyze existing public policies and programs and to make recommendations for the future.

The Reports of our Liaison Task Panels on Psychoactive Drug Use/Misuse and on Alcohol-Related Problems are contained in Volume IV of the Appendices to this Report. We urge that both be read.

Mental retardation presents its own set of complex problems. There are an estimated six million Americans who are mentally retarded. One-third have multiple

handicaps. During the past few years the Nation has developed a public awareness of and sensitivity to mental retardation. This has led to improved care in many instances, but much remains to be done.

At the beginning of our work we asked the President's Committee on Mental Retardation, which has been in existence for the past ten years, and the National Association for Retarded Citizens to provide us with their advice and guidance on how best to address the specific relationship between mental retardation and mental health. Both submitted reports. We also created a Liaison Task Panel on Mental Retardation which synthesized information from many sources into its own report for the Commission. These three reports are also contained in Volume IV of the Appendices.

We have incorporated into our Report several recommendations in the areas of research, prevention, and improved public understanding that refer specifically to mental retardation. We believe, however, that the problems of mental retardation are of national interest and require continuing study and the concern of all Americans. The Commission therefore recommends that the President, in consultation with the Secretary of Health, Education, and Welfare, reassess the role and mission of the President's Committee on Mental Retardation with the aim of providing it with direction for the future.

Community Supports

Throughout America, as in any society, there are personal and social networks of families, neighbors, and community organizations to which people naturally turn as they cope with their problems.[3]

Such assistance can help an individual through an emotional crisis, possibly preventing more serious disability. These supports are important adjuncts to more formal mental health services and can be especially valuable to individuals with chronic mental illness.

As we seek ways to improve mental health services, it is important to recognize the strengths and potential that various support networks bring to different communities and neighborhoods and to recognize the need to develop linkages between these systems and the formal mental health services system.

Families, friends, and neighbors are usually the first people to whom a person with a mental or emotional problem will turn or from whom support will be forthcoming. Children, adolescents, and the elderly frequently benefit most from this personal assistance and support. This is especially true in racial and ethnic communities which over the years have developed strong, culturally sensitive networks of support. Regardless of their form, families serve as buffers between their members and the larger society and can make important contributions to personal mental health.

Many individuals with problems turn for help to more organized groups and institutions within local communities such as churches and synagogues, schools, employers, unions, and civic clubs and voluntary organizations. For some of these, a helping role is natural. More people with emotional problems turn initially to clergy or other religious leaders and to traditional folk healers such as medicine men and *curanderos* than to mental health professionals. These individuals have traditionally ministered to the chronically ill and troubled. For others, supportive activities signal a new departure and a new dimension. Those employers and unions which recognize the emotional problems that can develop with respect to certain jobs or job changes, or from retirement and unemployment, and which have developed programs of social supports for workers undergoing stress, clearly are moving in a new direction important for the mental health of the community.

"Alternative" services have also expanded and diversified to meet mental health needs. A number of these "alternative" services explicitly define themselves as part of the mental health movement, combining attention to psychological problems with physical care and social activism to provide effective mental health services. Others are wary of being classified as mental health services, convinced that such a classification entails a medical perspective and implies authoritarian relationships and derogatory labeling.[4]

Self-help groups such as Alcoholics Anonymous have long played a role in helping people cope with their problems. Similar groups composed of individuals

with mental and emotional problems are in existence or are being formed all over America. Recently there has been a marked increase in new forms of formal volunteer programs, such as Foster Grandparents, which link volunteers to community services.

Schools, the civil and criminal justice system, and general health care providers also play important roles as personal and social supports.

—American public schools traditionally have been more than educational institutions. In many instances they have contributed to the sense of identity and shared purpose which exists in many neighborhoods and communities; and schools already are the setting for a variety of social, educational, and health care programs for people of all ages. When locally appropriate, they would seem to be logical settings for additional mental health-related functions.

—Many people with mental health problems become involved with the justice system. They need the same kind of social and community support systems that other people need. Many young people with mental and emotional problems who come to the attention of juvenile courts benefit from supportive neighborhood activities such as recreation and arts programs, educational supplements, close personal relationships with the volunteers and professionals who work in these programs, and community-based residential programs that serve as alternatives to incarceration in correctional institutions.

—Far greater numbers of people with emotional problems turn to primary health care providers than to mental health practitioners when they first seek help. Many who turn to the health system, however, could be helped by existing community support systems. Methods must be devised to increase the capability of people working in medical settings to recognize when patients need social support and to provide them with access to appropriate community support systems.

The personal and community supports described above, in addition to others, can provide a basic underpinning for mental health in our society. Personal and community supports, when they emphasize the strengths of individuals and families and not their weaknesses, and when they focus on health rather than sickness, may be able to help reduce the stigma often associated with seeking mental health care. These largely untapped community resources contain a great potential for innovation and creative commitment in maintaining health and providing needed human services. In spite of the recognized importance of community supports, even those that work well are too often ignored by human service agencies. Moreover, many professionals are not aware of, or comfortable with, certain elements of community support systems. The Nation can ill afford to waste such valuable resources. The Commission believes this is one of the most significant frontiers in mental health at all levels of care and recommends:

- **A major effort be developed in the area of personal and community supports which will:**
  - **a) recognize and strengthen the natural networks to which people belong and on which they depend;**
  - **b) identify the potential social support that formal institutions within communities can provide;**
  - **c) improve the linkages between community support networks and formal mental health services; and**
  - **d) initiate research to increase our knowledge of informal and formal community support systems and networks.**[5]

A Responsive Service System

A basic responsibility of America's public and private mental health services system is to make appropriate mental health care available to individuals with serious psychological disabilities, whether of an acute or chronic nature and whatever the underlying causes.

A responsive mental health service system should provide the most appropriate care in the least restrictive setting. Whenever possible, people should live at home and receive outpatient treatment in the community. When they cannot, the facility in which they are treated should offer the maximum possible independence. The special circumstances of those who use services should be reflected in the way we provide care. Treatment, whether in inpatient or outpatient settings, should be sensitive to patients' cultural and ethnic backgrounds and should respect their rights and dignity. No single form of treatment can meet the needs of all patients. No single system for delivering mental health services can meet the needs of all communities.

Our long-range goal for mental health services must be a comprehensive and integrated system of care that draws on the strengths of both the public and the private sector. The system should include a variety of programs and facilities staffed by appropriately trained personnel, with community-based services as the keystone. It must be accessible to all, yet responsive to populations with special needs and able to adapt to the changing circumstances of individual patients. The services offered should be coordinated, and continuity of care assured, within the mental health sector and among mental health systems and the health, social service, education, and income support systems. Because we can no longer afford a fragmented system that leaves many people unserved, there must be effective planning and accountability procedures. We must have adequate financing to ensure that people get help when they need it at costs reasonable to themselves and to the public. The rights and responsibilities of patients, families, providers of care, institutions, and communities must be clearly stated, understood, and enforced.

These goals will not be realized tomorrow or even next year. They are goals for a decade. In pursuit of these goals, we must develop new alliances between the public and private sectors and among Federal, State, and local governments to:

—fulfill the national commitment to develop a network of accessible community mental health services;

—establish a national priority to meet the needs of people with chronic mental illness; and

—plan for mental health services in a way that recognizes their close relationships to health and other human services.

Fulfilling the National Commitment to Community Mental Health Services

In our judgment, people are usually better off when they are cared for within their communities, near families, friends, and homes. Our assessment of the past twenty years shows that progress has been made toward this end. Mental health centers have moved services into communities where they previously did not exist. General hospitals have assumed a larger role in providing both inpatient and outpatient care. The number of mental health specialists practicing in the private sector has grown, as has the number of mental health facilities operated under private auspices. As a result, more mental health care is available and a wider range of services is offered. These services are provided in more accessible and diverse settings and more people are using the services.

For many, regardless of economic circumstances, community-based services are still unavailable. Many members of racial and ethnic minorities and the poor, both urban and rural, are still unserved, underserved, or inappropriately served. Some areas of the country and some special populations, such as migrant and seasonal farmworkers, are virtually unserved by mental health services. Restrictive and inflexible laws and regulations complicate the delivery of care to rural Americans and American Indians. Language and cultural barriers have prevented some minorities from receiving appropriate care. And children, adolescents, and the elderly have not been served in proportion to their needs.

If we are to serve those who need care, we must strengthen programs and services of demonstrated effectiveness.

But we must do more. We must encourage the creation of services where none exist and develop a means to supplement services where they are inadequate.

Establishing New Services

Over the past 15 years the Community Mental Health Centers Program has been the major Federal vehicle for providing comprehensive mental health services in local communities. Since 1963, over 1.5 billion Federal dollars have been invested directly in this program. By October of 1978 there will be 647 centers in operation throughout the country; another 57 centers will be funded but not operational; and an estimated 14 centers are now approved but unfunded.

A substantial number of mental health centers have made significant service contributions in their communities. The centers account for approximately 25 percent of the episodes of care provided in the special mental health services sector, and for less than 5 percent of expenditures for the direct care of the mentally ill.

Important questions, however, have been raised about the implementation of the Centers program. Since no one way of organizing services can fit the needs of all people and all communities, varying approaches for developing comprehensive community mental health services should be encouraged.

The Community Mental Health Centers Program as originally designed required communities to offer emergency, outpatient, inpatient, partial hospitalization, and consultation and education services. In 1975 the legislation was amended so that a community had to provide those five, plus seven additional services. All these services had to be available within two years of receiving the initial grant.[6]

These requirements reinforced a sound principle—the need for comprehensive mental health services. They have, however, excluded many communities which

needed services immediately but did not and may never require the array of services mandated by legislation. A way must be found for unserved and underserved communities to have mental health services without forcing them to assume the formidable responsibility of providing the full range of services.

There are other constraints placed on communities that want to develop mental health programs tailored to their needs. Many are unable to meet the requirements for matching funds or to attract the personnel needed to staff a full program. These communities must be allowed to begin on a smaller scale and build toward a comprehensive program at their own pace.

Finally, some populations with special needs, such as children, the elderly, and people with long-term mental disabilities, are not receiving services commensurate with their need. We must encourage the development of service delivery strategies to accommodate them.

To accomplish these objectives, the Commission recommends:

- **A new Federal grant program for community mental health services to:**
  a) **encourage the creation of necessary services where none exist;**
  b) **supplement existing services where they are inadequate; and**
  c) **increase the flexibility of communities in planning a comprehensive network of services.**

Just as certain communities might best meet their needs by beginning with the five essential services originally mandated by the Centers program, others might conclude that services for children and adolescents are the most appropriate point of departure. In either case this new Federal grant program would be the source of potential funding for the community. The Commission also recommends:

- **Priority in the new grant program be given to:**
  a) **unserved and underserved areas;**
  b) **services for children, adolescents, and the elderly;**
  c) **specialized services for racial and ethnic minority populations; and**
  d) **services for people with chronic mental illness.**

At the time of transition to the new program, priority should be given to funding approved but unfunded applications received under previous legislative authority, provided they are consistent with the purposes of the new program. To implement this new program, the Commission recommends:

- **An appropriation of at least $75 million in the first year and $100 million for each of the next two years.**[7]

Applicants for grants should be public or private, non-profit agencies. The National Institute of Mental Health should provide technical assistance to those who

need help in developing proposals. Evidence of governance or advisory boards with adequate consumer and citizen representation should be required. To assure accountability and that the program is needed and does not duplicate existing services, each application for funding under the new program should be consistent with priorities established in a mental health component of both the local Health Systems Agency and the State Health Plan. This review and approval process should include considerations at the local and State levels in accordance with the planning recommendations to follow. These are designed to insure coordinated planning for comprehensive services. To avoid fragmentation of services, the applicant should also be required to demonstrate a willingness and capacity to enter into appropriate working agreements with existing mental health agencies in the community.

Initial funding should be for a five-year period. In communities where there are no mental health services and an inability to meet requirements for matching funds, the Federal Government should provide complete funding. Over time, grantees should be able to apply for additional funds to add services which will lead to planned comprehensive networks of care. Existing community mental health centers should be encouraged to participate in the program. At the end of three years the program should be evaluated to see if it has accomplished its objectives.

We are aware that the Congress is considering amendments to the legislation authorizing the Community Mental Health Centers Program. While some of these amendments would improve the program, they would not fully accomplish what we believe must be done to encourage the development of networks of comprehensive mental health services in a sequence and at a pace appropriate to individual communities. The need exists for the new community mental health services program we have proposed. Until this new program is enacted, the momentum toward community mental health services generated by the Centers program should be maintained. The National Institute of Mental Health should focus its technical assistance efforts on developing proposals for unserved and underserved areas. The Commission recommends that under existing or amended community mental health centers legislation:

- **The National Institute of Mental Health fund approved applications in those areas identified as unserved or underserved.**

Strengthening Existing Programs and Services

Community mental health centers recently have been subjected to heated criticism. Some observers point out the relatively limited role centers have played in key areas such as prevention. Others criticize them for straying from traditional psychiatric concepts and medically oriented mental health care. Many of these critics fail to take into account the fact that the centers have had to contend simultaneously with a proliferation of service requirements and a reduction of fiscal support.

Community mental health centers were developed on the premise that non-Federal resources would eventually replace Federal dollars as the basic source of support for the program. However, many centers which have reached, or are reaching, the end of their eight-year period of Federal funding may be forced to

reduce or dismantle existing services. Fiscal retrenchment by State and local governments and limitations on mental health benefits, which exist in both public and private financing programs, have reduced the total amount of money the centers have been able to attract.

If centers are forced to cut back, there is real danger that many gains of the last 15 years will be lost. The first services sacrificed are likely to be those of prevention, outreach, case management, consultation, and education—services which are rarely reimbursable. These are essential to the development of a comprehensive system of care. We believe the Federal Government has a responsibility to assure their continued availability and therefore the Commission recommends:

- **Limited Federal funding for certain services which centers now provide on a non-reimbursable basis.[8]**

There are additional steps that must be taken to strengthen existing programs and services. The Commission recommends:

- **Greater flexibility in delineating catchment area boundaries.[9]**
- **Encouragement of cross catchment area program sharing.[10]**
- **Allowing greater variation in governance and advisory board arrangements so that they properly reflect local circumstances.[11]**
- **Assistance for the members of mental health advisory/governance boards in dealing with problems related to the planning and delivery of mental health care.[12]**

General Health and Mental Health Services

General health care settings represent an important resource for mental health care in the community. There is ample evidence that emotional stress is often related to physical illness and that many physical disorders coexist with psychological disorders. While general health care settings frequently serve as an entry point to the mental health care system, many millions of persons with some level of mental disorder are never referred to mental health specialists. They are cared for by office-based practitioners, in industrial health care settings, in homes, in general hospital outpatient clinics and emergency rooms.

While the interdependence of the mental health and general health system is evident, cooperative working arrangements between health care settings and community mental health service programs are rare. If we are to develop a truly comprehensive system of mental health services at the community level, greater attention must be paid to the relationship between health and mental health.[13]

Populations with Special Needs

Even if the steps we have recommended are taken, there still will be significant barriers to appropriate mental health care for minority groups in our ethnically diverse Nation. Many patients needing treatment will not seek care if providers are

not sensitive to their culture or are unable to speak their language. To meet the particular needs of minority populations, the Commission recommends that:

- **Mental health service programs should:**
  a) **actively involve ethnic and racial minorities in planning and developing services;**
  b) **provide culturally relevant services and staff them with bilingual, bicultural personnel; and**
  c) **contract with minority community-based organizations for delivery of services.**

Inadequate numbers of minority individuals are in decision-making positions in mental health funding, planning, and quality assurance agencies at Federal, State, and local levels. Strenuous efforts must be made to employ qualified minority persons in these positions.

Special populations may be defined by age as well as by race, sex, and ethnicity. Childhood, adolescence, and old age are times of life when service needs are multiple. Integration and coordination of care are essential because the need often exists to involve other human services. Home care for the elderly, group homes and residential schools for adolescents, and case managers for children are frequently necessary. The Commission has been impressed by the lack of relationship between the allocation of funds for services and assessment of the relative needs of these age-related groups. This should not be so. Therefore the Commission recommends that:

- **The Department of Health, Education, and Welfare require that Health Systems Agencies perform biannually a culturally relevant assessment of mental health needs. Special attention should be given to ascertaining the needs of children, adolescents, and the elderly.**

The new Federal grant program proposed earlier in this Report was devised in part to improve the availability of services for populations with special needs. As we move more energetically to meet these needs, the National Institute of Mental Health should examine ways of strengthening existing organizational units that focus on underserved populations. In addition, we believe that all federally funded mental health programs should include in their annual reports information on the extent to which populations with special needs have been served. Advocacy groups at the national level should have access to these annual reports so that they can evaluate the success of the Department of Health, Education, and Welfare in this respect. The Commission also recommends that:

- **Reviews for grant continuation direct careful attention to whether the applicant has demonstrated a significant effort toward meeting the special needs of high-risk populations.**

In monitoring the extent to which such populations are being served, we must not conclude that all problems are the fault of the service delivery system. Some are a result of how we finance care. For example, a major barrier to outpatient care for populations with special needs is imposed by the public mechanisms for financing their mental health care—Medicare and Medicaid.

While these issues are described in detail and our recommendations set forth in the next section of this Report, we feel compelled to note that Federal financing mechanisms have often worked at cross-purposes to federally initiated service delivery programs. Thé Community Mental Health Centers Program implies a strong Federal commitment to outpatient mental health care and to the providing of services in the least restrictive, most appropriate setting. In contrast, Medicare and Medicaid programs provide limited mental health benefits, and those are heavily biased toward inpatient care. We cannot meet the needs of the poor, the disabled, and the elderly for appropriate mental health services without providing means to pay for such care.

Establishing a National Priority to Meet the Needs of People with Chronic Mental Illness

The 1961 Final Report of the Joint Commission on Mental Illness and Health called for a national policy to improve the care of people with chronic mental illness. Many mentally disabled persons, however, still enter, reenter, or remain in public institutions when they could be treated in the community. Many of these institutions are still large, isolated, and understaffed. When patients are discharged there is inadequate planning for follow-up care. People with chronic mental disabilities frequently live in nursing homes, foster care homes, room and board facilities, and "welfare hotels," many of which do not provide adequate care. Medication, often the only treatment offered, may not be properly monitored. Many have found that local facilities, residences, and services offer no improvement over large State hospitals.

A National Plan

An adequate, humane system of mental health care cannot exist until the special needs of Americans with long-term and severe mental disabilities are met, and until Federal, State, and local governments share the responsibility for meeting this goal. As a first step, the Commission recommends that:

- **The Department of Health, Education, and Welfare, in consultation with State and local governments, develop a national plan for:**
  - **a) the continued phasing down and where appropriate closing of large State mental hospitals;**
  - **b) upgrading service quality in those State hospitals that remain; and**
  - **c) allocating increased resources for the development of comprehensive, integrated systems of care which include community-based services and the remaining smaller State hospitals.**

The national plan should serve as a frame of reference and be flexible enough to account for differences within individual States. It should address the following goals:

—minimize the need for institutional care;

—assure high quality care for those who must be institutionalized;

—provide aftercare services and alternatives to hospitalization in the community;

—provide retraining and job placement for personnel displaced by the phase-down process;[14] and

—encourage the use of vacated State hospital facilities for human service activities.

While a national plan will provide a statement of commitment and outline broad policy objectives, there is a need to define clearly the roles and responsibilities assumed by the individual States and the Federal Government. This can be done if the States describe the approach they intend to take to meet the national goals, and if the Federal Government negotiates contracts with each State to provide the resources necessary to achieve these goals.

In addition, the contract can provide a mechanism for consolidating Federal funds which States currently receive for services to persons with chronic mental illness and for augmenting those funds with new money. These contracts should be performance contracts.[15] A State which met the terms of the contract would continue to receive money. A State which did not would have its funds withdrawn. The Commission therefore recommends that:

- **Each State health plan describe the approach the State intends to take or is taking to meet the goals of the national plan.**
- **The Department of Health, Education, and Welfare develop a model for performance contracts in order that national goals for phasing down State hospitals, upgrading the quality of care in those that remain, and improving aftercare services can be achieved in a mutually agreed upon manner.[16]**
- **The Department of Health, Education, and Welfare seek authorization for and appropriations of up to 50 million new dollars for each of the next five years to assist in reaching the goals agreed to in these performance contracts.**

Developing Resources in the Community

When a person is discharged from a State hospital or when attempts are made to find alternatives to hospitalization, it is often assumed that adequate 24-hour care, a range of living arrangements, and opportunities for treatment, resocialization, vocational rehabilitation, and employment are available. It is also often assumed that there are links between the hospital and the community and among service programs in the community. However, these necessary resources and links frequently do not exist. Their absence makes it difficult, if not impossible, for many people with chronic mental illness to bridge the gap between the State hospital and community care, or to organize for themselves the needed array of services within the community.

We encourage efforts at decentralization which link State hospital units to specified communities. We also encourage joint planning and interagency liaison within the community.

Case Management. Strategies focused solely on organizations are not enough. A human link is required. A case manager can provide this link and assist in assuring continuity of care and a coordinated program of services. Case management is an expediting service. The case manager should be sensitive to the disabled person's needs, knowledgeable about government and private agencies that provide housing, income maintenance, mental health, health, and social services, and should be in close touch with the community's formal and informal support systems. With these functions in mind, the Commission recommends that:

- **State mental health authorities develop a case management system for each geographic service area within the State.**[17]

Long-Term 24-Hour Care. Today, more chronically mentally ill people are in Medicaid-supported nursing homes than in mental hospitals. Most are placed in a class of nursing homes called Intermediate Care Facilities. Some Medicaid requirements for these facilities are irrelevant or excessive for mentally ill patients. They not only increase construction costs in many cases, they also encourage the establishment of larger institutions rather than more desirable, smaller, home-like facilities.

At the same time, they say nothing of the special services needed by the mentally ill, and they are designed primarily for geriatric patients rather than for people of all ages. Since nearly 30 percent of the direct expenditures for mental health care currently go to nursing homes, we are making a huge investment in a setting that is not optimal for the needs of the chronically mentally ill. To develop facilities that meet the needs of the chronically mentally ill, the Commission recommends that:

- **A new class of Intermediate Care Facilities-Mental Health (ICF-MH) be created within the Medicaid program and linked with local organized systems of mental health care.**

Short-Term Hospitalization. People with chronic mental disabilities may at times require inpatient treatment. For those who require longer term hospitalization, smaller State hospitals will continue to be an important resource. For most, only short-term hospitalization will be necessary. We believe this treatment can best be provided in community-based facilities such as general hospitals, private psychiatric hospitals, and community mental health centers. At present, however, some communities do not have enough psychiatric beds to accommodate people who need short-term inpatient care. Community psychiatric beds must be available before State hospital beds are eliminated. Though this increase will eventually be offset by a decrease in the number of State hospital beds, health planning agencies must be prepared to accept this temporary overlap. The Commission therefore recommends that:

- **Based upon adequate documentation, Health Systems Agencies endorse the issuance of certificates of need for the allocation of a limited number of psychiatric beds in communities prior to the reduction of State hospital beds.**

Living Arrangements. If chronically mentally ill people are to be cared for in their own communities, living arrangements must be available that are adequate and affordable. Some will want, and be able, to live alone. Others might prefer to live with their families.

Still others will need structured and protected environments. These options have not been widely available in the past. They are not widely available now. The recommendations that follow are intended to increase the range of choices available to the chronically mentally ill who live in communities.

Group living arrangements often provide the support necessary for patients to remain in the community. Current Housing and Urban Development regulations prohibit rental assistance for persons living in group residences because the quarters have shared kitchen and bathroom facilities. Former patients should not be excluded from rental assistance because of their special need for group living arrangements. The Commission recommends that:

- **The Department of Housing and Urban Development promulgate proposed regulations making rental assistance available to persons living in group homes.**

Assuring equal opportunity for the mentally ill in public housing programs would provide another housing alternative for people with chronic mental illness. The Commission therefore recommends that:

- **In the allocation of public housing, equal opportunity should be given to people with chronic mental illness discharged from institutions or at risk of hospitalization.**

In the community, the income of many citizens with chronic mental disabilities is limited to support provided through the Supplemental Security Income program (SSI). But SSI payments do not take into account needs for special housing and supportive services. If a mentally disabled person lives in a group environment or "in the household of another," including family, SSI payments are reduced. This state of affairs is unfortunate on two counts: it can place an undue strain upon already taxed family resources; it fails to take into account the increased programmatic cost associated with supportive living arrangements such as those provided by residential facilities and halfway houses.

This is a particular dilemma for those about to be discharged from a State hospital. If they are discharged, they may get freedom but little help. The alternatives,

remaining in the hospital or transfer to a Medicaid-covered nursing home, may be more restrictive than necessary and not appropriate to the individual.

Existing programs can be modified so that people with chronic mental disabilities will have greater access to appropriate supportive living arrangements. To accomplish this the Commission recommends that:

- **The basic Supplemental Security Income benefit be increased to meet the needs of those persons who require specialized residential programs in the community.**
- **If a person "lives in the household of another," the Supplemental Security Income benefit should not be reduced.**
- **The budget ceiling of Title XX of the Social Security Act be raised for the purpose of allocating funds so people inappropriately placed in medical facilities can be transferred to residences in the community.[18]**

The Commission emphasizes the need for further study and for further efforts to resolve the complex problems that surround the issue of providing decent, humane living environments for chronically mentally disabled people.

Employment and Employability. Chronically mentally ill people have special needs in relation to work. Because employers raise questions about their productivity, many have difficulty finding jobs. In other instances, employment is not a reasonable goal. To address these issues, the Commission urges the development of tax credits as incentives to employers to hire chronically disabled persons able to work, and a broader range of vocational rehabilitation and sheltered employment opportunities for chronically disabled persons unable to work.

Planning for Mental Health Services

Poor planning can confuse priorities, divert administrative energies, and waste money. The victims of this disarray are the people who need care, the local programs and agencies which provide it, and the taxpayers who must pay for it. If we want to build a comprehensive, coordinated, and effective mental health care system in the future, we must plan for it today. The planning process which now exists is not adequate to the task.

Information and Data Gathering

Adequate planning cannot be accomplished without reliable information. Presently, various Federal, State, and local agencies request different information on the personal and clinical characteristics of the people served, on the types of services provided, and on the expenditures for services. A recent inventory of federally required State plans which affect the delivery of comprehensive services to the mentally disabled identified eight separate planning authorities that request similar information but use different planning mechanisms, reporting formats, and time cycles. Even within the Alcohol, Drug Abuse, and Mental Health Administration, each of the three Institutes has its own reporting system.

The Commission believes it would be useful to have a single, uniform information system adequate to the needs of local, State, and Federal Government. At a minimum, Federal reporting systems should give consideration to local

information needs by involving State and local agencies in the design of information systems. As a first step, the Commission recommends that:

- **The Administrator of the Alcohol, Drug Abuse, and Mental Health Administration take the necessary steps to consolidate the information and data-gathering requirements of the National Institute of Mental Health, the National Institute on Drug Abuse, and the National Institute on Alcohol Abuse and Alcoholism into a single reporting system.**

Quality Assurance and Program Evaluation

While it is important to have adequate and current information on existing resources and their utilization, it is essential to have mechanisms to determine whether service settings are adequate, whether the care given is well provided, and whether the services and programs we sponsor are achieving the objectives for which they were established. Accreditation and licensing procedures, peer review, and program evaluation are basic techniques for accomplishing these ends. To facilitate the review of the quality of mental health services and service settings and to enhance our program evaluation capacity, the Commission recommends that:

- **Professional Standards Review Organizations make provision for multi-disciplinary peer review of mental health care provided in multi-disciplinary mental health settings.[19]**
- **The Department of Health, Education, and Welfare combine into a single survey the inspections required of an institution for receipt of Medicare, Medicaid, and categorical health and mental health grants.[20]**
- **The National Institute of Mental Health allocate to a selected number of programs an award of 10 percent in excess of their grant for the purpose of developing and assessing techniques to evaluate mental health service delivery.**

The Planning Process

A mental health plan should not only address issues related to the delivery of care by the mental health sector. It must also speak to the need for a comprehensive array of health and other human services. We strongly advocate a process that encourages coordinated planning between the mental health system and other human service systems. To assure that the differing priorities are adequately met, basic assessments of need should be made at the local or regional level.

An excellent point of departure for applying these principles exists in relation to the health and mental health systems. Since 1975, two major Federal laws have required extensive mental health planning activities—the National Health Planning and Resources Development Act of 1974 and the Community Mental Health Centers Act, as amended in 1975. Each requires the preparation of statewide and regional mental health plans. Congress is currently considering amendments to these laws. We hope that the Congress will use this opportunity to provide a framework for

coordinated planning. This collaborative approach should involve a significant sharing of resources and decision-making authority. With this in mind, the Commission recommends:

- **Changes in existing statutes, regulations, and policies to facilitate:**
  a) **coordinated health and mental health planning at the local and State level;**[21]
  b) **increased participation in the general health planning process by citizens knowledgeable about, and representative of, the interests of mental health, alcoholism, and drug misuse;**[22] **and**
  c) **provision for the resolution of differences in planning goals between the health care and mental health care sectors.**[23]

Mental health services are frequently delivered in conjunction with vocational rehabilitation, education, and social services. Considerable amounts of Federal funds are made available to mentally ill persons through Title XX of the Social Security Act, the Vocational Rehabilitation Amendments of 1974, and the Education for All Handicapped Children Act of 1975. Neither the requirements for planning under these acts, nor those governing mental health planning, specifically acknowledge the interdependence of these systems. The Commission recommends:

- **Changes in planning guidelines to ensure that the needs of the mentally disabled for education, housing, vocational rehabilitation, and social services are adequately met.**[24]

Insurance for the Future

Many who need mental health care cannot afford the help they require. It is pointless to design, plan, and provide service systems if people do not have the means to pay for them. It is shortsighted to devise financing mechanisms that promote more restrictive and expensive forms of treatment when other less expensive options would be as effective. It is wasteful to invest money in establishing programs through project grants and then deprive the programs of access to third-party reimbursement funds to support their services once the grants are ended. Yet these elements form the basis of today's national policy for financing mental health care.

What we have now is a patchwork of public and private arrangements for financing mental health care. What we need is a more comprehensive and coordinated public and private strategy for financing mental health service, where payment is based upon the need for care, not diagnosis, and upon the appropriateness of care, not the discipline of the provider. We firmly believe that a national health insurance program which includes appropriate coverage for mental health care offers the most effective means of providing adequate financing for the mental health needs of all Americans, regardless of income.

Principles for Financing Care

When we consider the present and look to the future, the Commission finds itself most concerned about the basic principles which we believe ought to govern the current public and private financing of mental health care as well as plans for a future national health insurance program. Adherence to these principles now would improve the availability and quality of mental health care. The Commission therefore recommends that:

- **Any national health insurance program and all existing private health insurance programs and public programs financing mental health care, such as Medicare and Medicaid, be governed by the following guidelines:**
  - a) ***Benefits*. A reasonable array of emergency, outpatient, and inpatient care should be covered, including partial hospitalization and 24-hour residential treatment for children and adolescents, sufficient to permit treatment of mental disorders in the most appropriate and least restrictive setting.**
  - b) ***Reimbursement*. Reimbursement should be provided for those mental health services involving the direct care of the patient and for care rendered to others where it is integral to the patient's treatment.**

In the case of care provided in organized settings or systems of care, reimbursement should be made to the system rather than to the practitioner providing the care. All covered services must be rendered by, or be under the direct clinical supervision of, a physician, psychologist, social worker, or nurse with an earned doctorate or master's degree and with appropriate clinical competence as established by State licensure or certification by a national body.

Direct reimbursement should be made to independent qualified mental health practitioners as defined by national health insurance legislation. This issue should be re-examined under existing legislation.

Adequate provision for controlling costs and peer review should exist.

c) ***Cost Sharing*. There should be minimal patient-borne cost sharing for emergency care. In all other instances, patient-borne cost sharing, through copayments and deductibles for evaluation, diagnosis, and short-term therapy, should be no greater than that for a comparable course of physical illness.**

d) ***Freedom of Choice*. The consumer should have a choice of provider and provider systems, and procedures should be developed to ensure that individuals have the necessary knowledge and information to make an effective choice.**

If these principles were adhered to, many of the financial barriers that currently prevent individuals from receiving needed care would be eliminated and many of the fiscal dilemmas confronting organized mental health care settings in the community would be resolved. We would have a more rational and systematic way to ensure the availability of an appropriate array of mental health services than we now have, and we would have done much to correct the strong bias toward inpatient and institutional care currently exhibited by public and private health insurance programs.

As we move toward implementing these principles, however, there are other steps that should be taken, including:

—Short-range changes in the financing of mental health services through existing public mechanisms and through private insurance plans; and

—A new approach for financing long-term care for persons with chronic mental illness.

Medicare

When Medicare was enacted in 1965, it was modeled after the best private health insurance programs of the time and intended to be an exemplar for progressive public financing of health care. Over the past decade, however, no significant changes have been made in the program. It has not kept up with advances in the delivery of services or with advances made by private insurance programs in financing health care. While Medicare may have been intended to mirror the most progressive private insurance programs of the 1960's, those who see it as a model for national health insurance should look more critically.

Nowhere are the deficiencies of the Medicare program more apparent than in the area of financing mental health care. The program has set an unfortunate precedent in public financing efforts for the discriminatory treatment of people with mental disability. For example, inpatient care in psychiatric hospitals is limited to 190 days over a person's entire life span. In contrast, limitations for inpatient care in general hospitals are framed in terms of each episode of illness. Not only is there a 60 day lifetime reserve, but a person is eligible for 90 days of coverage for each episode of illness, regardless of how many times the person becomes ill.

Further, organized mental health care systems cannot qualify as providers of outpatient services under Medicare unless operated by a general hospital, while physician-directed health care clinics such as neighborhood health centers can. In addition, a patient with physical illness pays 20 percent of the bill for outpatient care, but the same patient with a mental illness must pay 50 percent of the bill up to $500 and 100 percent thereafter.

As restrictive as the original Medicare legislation was in regard to financing ambulatory mental health treatment, inflation has further reduced the coverage endorsed by Congress. Since 1965, charges for psychiatric office visits have increased by almost 70 percent. With no corresponding increase in the maximum outpatient benefit, today's elderly are reimbursed for less than half of the services they would have been able to receive a decade ago. As a result of these restrictions, often the only option for diagnosing the problems of or treating the elderly with mental disability is to hospitalize them.

If we are to reduce the financial barriers to mental health services for the elderly, the discriminatory treatment of mental health services under the provisions of Medicare must be eliminated. The Commission recommends:

- **Amending current Medicare legislation so that:**
  - **a) community mental health centers and other organized systems of community mental health care be given provider status;**
  - **b) the allowable reimbursement for the outpatient treatment of mental conditions be increased to at least $750 in any calendar year;**
  - **c) the beneficiary coinsurance be reduced from 50 percent to 20 percent to conform to Medicare coinsurance requirements for physical illness;**
  - **d) coverage for inpatient care of psychiatric disorders in acute care settings be extended so it is equivalent to that provided for physical illness; and**
  - **e) two days of partial hospitalization be allowed for each day of inpatient care.**

Medicaid

The Medicaid program reveals problems even more complex than those found with Medicare:

Medicaid is 53 different programs with significantly different characteristics. Within fairly broad Federal guidelines, States have considerable latitude to respond to local needs, capabilities, and pressures. For example, in poor States, less than 20

percent of the poverty population receive help in paying their health care bills. In other States, particularly in the industrialized North, the number of those receiving assistance is equal to more than 125 percent of the "poverty population."

Medicaid is a welfare program. To be eligible for Medicaid, an individual or family must not only be poor but must be "categorically" poor, either aged, blind, or disabled, or a member of a family with dependent children where only one parent is capable of providing financial support. Intact families, the working poor, single people, childless couples, and many others between the ages of twenty-one and sixty-five do not generally receive Medicaid assistance. Indeed, more than one of every three poor persons do not meet the eligibility requirements of the Medicaid program and thus may be deprived of mental health care.

Mental health services under Medicaid are extremely limited. Medicaid provides Federal matching funds for only a limited array of mental health services. Those that are covered are restricted in ways that services for the physically ill are not. States may, at their option, also be federally reimbursed for hospital care provided to persons under age twenty-one or over age sixty-four in a psychiatric facility; for nursing home care under limited circumstances and only for individuals of specified age; and for certain partial hospitalization and clinic services. States are also free to define the amount, scope, and duration of services—including federally mandated services—they will cover.

Medicaid permits States to reduce services by manipulating reimbursement rates. States may not deny services to a beneficiary on the basis of the patient's diagnosis, but they can influence the availability of care through their ability to determine rates of compensation. In some States, community mental health centers are reimbursed for as little as 25 percent of their costs. In other States, psychiatrists are reimbursed for as little as $6 per hour-long visit. This rate is equivalent to that paid other physicians for a routine office visit, which often lasts only 5 or 10 minutes. As a result, many health care providers refuse to participate in Medicaid, and many people eligible for Medicaid are denied access to needed services. A person who needs care cannot receive assistance if the State plan includes health and mental health benefits but the reimbursement rate is so low that the services are not provided.

Medicaid favors institutional care. Almost 70 percent of the mental health care reimbursed under Medicaid in fiscal year 1977 was for institutional services—these include State and county hospitals, private mental institutions, and nursing homes. Indeed, over half of all Medicaid funds expended for mental health services went to nursing homes.

It is the belief of this Commission that correcting deficiencies in the financing of mental health services for low income populations through Medicaid should be approached from at least two directions: improving the existing structure of the Medicaid program, and making significant changes in the statute to establish more reasonable eligibility and benefit provisions for low income populations. With this in mind, the Commission recommends that:

- **The Secretary of Health, Education, and Welfare take those steps necessary to assure that:**
  - **a) States have effective systems to prevent discrimination on the basis of diagnosis;**

b) **mental health services be made available within Medicaid child health programs;**
c) **State Medicaid plans offer a reasonable amount of ambulatory mental health services; and**
d) **State Medicaid reimbursement policies not limit the availability of mental health services.**

- **The Secretary of Health, Education, and Welfare develop legislative proposals to amend Medicaid to:**
  a) **establish national minimum eligibility standards based on income and assets rather than on categorical requirements so that everyone who satisfied the definition of financial need would be eligible for assistance;**
  b) **establish national minimum mental health benefits to be included in every Medicaid State Plan; and**
  c) **remove provisions that allow for any discrimination in the allocation of services on the basis of age.**

Private Health Insurance

While inpatient mental health coverage is substantial in many major private insurance policies, outpatient mental health benefits are more restricted and vary widely. Consistent with our emphasis on the importance of outpatient care, we believe that a limited outpatient benefit should be provided by all private health insurance plans, and the Commission recommends that:

- **States be encouraged to require that private health insurers offer an outpatient mental health benefit with low or no copayment for initial visits and extend coverage to family members whose treatment is vital to the care of the individual receiving benefits under the plan.**

The Federal Government also should encourage private insurers to provide mental health benefits comparable to general health benefits. This would eliminate a primary barrier to mental health care for most working Americans and could be done before the specifics of national health insurance become clear. The Commission therefore recommends that:

- **The Secretary of Health, Education, and Welfare propose legislation to encourage employers to include mental health coverage for emergency, outpatient, partial hospitalization, and inpatient services in the health insurance plans offered their employees.**

One additional matter merits attention: the need to develop an adequate base of information for the mental health component of any national health insurance program. A study of States which have already implemented mandatory mental health benefits for private health insurance plans can help answer questions on the

cost of mental health benefits for national health insurance planners. The study could explore the current cost of providing specific mental health services in public and private settings and organizations. Attention could also be paid to shifts in funding and utilization of mental health and general health services which occur when a segment of the population receives an increased benefit covering mental health care, and to the effect of increased mental health coverage on the utilization and cost of general health care services. The Commission therefore recommends that:

- **The Department of Health, Education, and Welfare conduct a study of mental health costs, focused on those States which have enacted some form of mandatory mental health benefits for private health insurance plans.**

Basic Support for People with Chronic Disabilities

In the section of this Report dealing with mental health services we have described the need of people with chronic mental illness for decent, humane housing, adequate nutrition, and other supportive services. Above all, they need a way to purchase these services or to have the services purchased for them. The money to pay for the entire range of services should not be tied exclusively to the health care system. We have already recommended certain ways in which existing programs could be modified to make these needed services available.

We favor, in principle, a system that enables individuals to receive income support benefits directly. Disabled individuals, their families, or their legally appointed guardians, if they wish or need such assistance, should have maximum possible autonomy in choosing a placement and using the disability benefit.

Two distinct types of financial assistance should be recognized: reimbursement for specified medical expenses, properly part of the health insurance system; and social welfare costs, properly part of an income maintenance program designed to recognize the unique circumstances and needs of persons with any type of disability, physical or mental.

The fact that our current system uses health insurance to pay nonmedical costs related to caring for the chronically disabled argues for a new approach to financing their care. Accordingly, the Commission recommends:

- **The Department of Health, Education, and Welfare explore the feasibility of creating a new system to meet the costs of chronic mental disability, either as an extension or modification of the Supplemental Security Income program or as a new federally financed income support system.**

New Directions for Personnel

The quality of mental health care depends ultimately on the knowledge, skills, and sensitivity of those providing it. We can build a network of comprehensive services and provide people with the means to pay for the services but accomplish little in the absence of skilled personnel to meet the diverse needs of those requiring care.

In its preface to the Health Professions Educational Assistance Act of 1976, the Congress stated that ". . .the Federal Government shares the responsibility of assuring. . . [that] qualified personnel are available to meet the health care needs of the American people. It is, therefore, appropriate to provide for the education and training of such personnel. . . ."

The Commission concurs with this statement and believes it has special relevance for mental health.

Since the establishment of the National Institute of Mental Health in 1946, the policy of the Federal Government with respect to mental health personnel has been to increase the number of qualified specialists. Implicit in this policy was the assumption that an increase in numbers would help to assure that all Americans had access to needed care. This assumption has not proved to be correct.

There has been a marked increase in the number of professional and paraprofessional mental health practitioners. However, rural areas, small towns, and poor urban areas still have only a fraction of the personnel they need. Many mental health facilities have a shortage of trained personnel. The mental health professions still have too few minority members. There is a shortage of specialists trained to work with children, adolescents, and the elderly.

If these problems are to be addressed during the next decade, Federal mental health personnel policy must be redirected. We believe the three major objectives of a new policy should be to:

—encourage mental health specialists to work in areas and settings where severe shortages exist;

—increase the number of qualified minority personnel in the mental health professions, and the number of mental health personnel trained to deal with the special problems of children, adolescents, and the elderly; and

—assure that the skills and knowledge of mental health personnel are appropriate to the needs of those they serve.

Since 1969, Federal support for mental health personnel has been steadily reduced and some have urged that it be phased out. In our opinion, these problems, affecting as they do the poor, minorities, the rural population, children, the elderly, and those dependent upon public facilities, cannot be solved without Federal support. Sufficient resources must be assured in the transition period and in the future.

Personnel for Unmet Needs

If our goal is to make available high quality mental health care to all Americans, there must be specialists who can meet the needs of the individual living in a rural area or smaller town, the child with a severe learning disability, the troubled adolescent, the disturbed person who cannot speak English well, the young adult with a chronic mental disability, and the depressed older person. We do not have enough such specialists today.

Maldistribution of Mental Health Personnel

The major mental health personnel problem facing the country is not one of inadequate numbers. It is, more precisely, one of the maldistribution of personnel. There are proportionately fewer mental health practitioners in rural areas, smaller towns, and poor urban communities. Public mental health facilities, particularly State mental hospitals and community mental health centers, are often unable to recruit and retain personnel.

The choices professionals make about where to practice are, to some degree, influenced by the nature of their training. Large State hospitals are rarely viewed as ideal training sites. The needs, culture, values, and special problems confronting the underserved are not well represented in curricula. Limited attention is given to developing the specific skills necessary to work in organized care settings or with populations that have special needs.

To encourage mental health practitioners to work where they are needed, to provide them with the knowledge and skills necessary to deal with a wide range of mental health problems, and to cultivate the sensitivity and competence required to relate to people from diverse backgrounds and differing lifestyles, the Commission recommends that:

- **Federal support for students in the core mental health professions be in the form of loans or scholarships which can be repaid by a period of service in designated geographic areas or facilities where there is a shortage of personnel.**[25]
- **Grants and contracts to educational institutions for the training of mental health specialists be awarded only to programs specifically aimed at meeting major service delivery priorities or the needs of underserved populations.**[26]

A Federal effort can greatly aid but cannot by itself solve the long-range problem of providing mental health personnel where shortages exist. In the final analysis, people will not work in areas and facilities that are unattractive and that do not provide opportunities for professional growth. Economic, career development, and educational incentives have all been considered by the Commission. We believe many are feasible, but we also believe States and local mental health authorities and agencies must determine which initiative is appropriate for them. We strongly urge them to do so.[27]

In recent years there has been a reduction in the numbers of American medical graduates entering psychiatric residency training. A severe restriction has also been

placed on the entrance into the country of foreign medical graduates, many of whom enter psychiatric residency training and practice in State hospitals. Over half the psychiatrists and other physicians staffing these facilities are graduates of foreign medical schools. Even such States as New York and Connecticut, which have a comparatively ample supply of psychiatrists, depend on foreign medical graduates for approximately 70 percent of the State hospital physician staff. If adequate mental health services are to be provided in areas where shortages already exist, steps must be taken to assure that the present supply of psychiatrists is at least maintained. Accordingly, the Commission recommends that:

- **The Health Professions Educational Assistance Act be amended to:**
  a) **designate psychiatry as a medical shortage specialty and require medical schools to set aside a certain proportion of their residency positions for this discipline; and**
  b) **permit those medical students who have an obligation to serve in the National Health Service Corps to defer such service until completion of psychiatric and/or child psychiatric residency training.**[28]

Minority Mental Health Personnel

Racial minorities remain greatly underrepresented in the mental health disciplines. This is particularly true of psychiatry and psychology.[29] While efforts have been made to increase the number of minority students being trained, decreases in the Federal mental health personnel budgets over the past few years have slowed this trend and threaten to reverse it. The Commission believes these efforts deserve higher priority in the allocation of funds.

A multi-level effort with specified goals must be undertaken if we are to increase the number of minority mental health professionals who provide service as well as the number who are involved in teaching, research, and administration. To accomplish these goals, the Commission recommends that:

- **The Department of Health, Education, and Welfare:**
  a) **at the high school level, develop special projects to interest minority high school students in mental health careers and augment them by a program of summer and part-time internships which provide work opportunities in mental health facilities and programs;**
  b) **at the college level, develop a program to provide scholarship support in the social, behavioral, and biomedical sciences to outstanding juniors and seniors interested in graduate training in the mental health professions. Stipends for summer jobs in mental health settings should also be provided;**
  c) **at the graduate level, expand the minority fellowship program funded by the National Institute of Mental Health and administered by various professional associations to include trainees in psychiatry, psychology, psychiatric social work, and psychiatric nursing who are planning clinical, administrative, or academic careers, and**

d) **at the faculty level, develop a fellowship program to enable faculty of academic institutions engaged primarily in educating minority students to complete their doctoral work or to receive post-doctoral training.**

Children, Adolescents, and the Elderly

The Commission is particularly troubled by the lack of people trained specifically to work with children, adolescents, and the elderly. These groups comprise more than half the Nation's population, but they are among those receiving the fewest mental health services. Since the interplay between socioeconomic, cultural, biological, and psychological factors is so profound during these life stages, those who provide care must have highly specialized knowledge and skills. Mental health care to children, adolescents, and the elderly often requires professionals who can work well with paraprofessionals, volunteers, and individuals working in the other human services. Few educational programs exist to train such people,[30] and the result is a shortage of specialists. The Commission therefore recommends that:

- **The Department of Health, Education, and Welfare fund efforts designed to increase the number of mental health professionals trained to work with children, adolescents, and the elderly with the provisions that:**
  a) **programs include training in supervision, administration and consultation as well as in diagnosis and treatment;**
  b) **a reasonable amount of faculty supervised training be given in such facilities as schools, hospitals, clinics, nursing homes, and senior citizen programs; and**
  c) **students receiving scholarship or loan support be required to repay them by service in publicly funded facilities or other shortage areas.**

Special Education, Career Development, and Planning

In our judgment, the recommendations we have made pertaining to personnel to meet the needs of underserved individuals represent our first priority. There are, however, other actions which could further enhance the responsiveness of the service delivery system and the quality of care provided.

Special Training Projects

Many more individuals with emotional problems receive care from the general health sector than from the specialized mental health sector. Because of this, it is important that primary care practitioners be able to recognize the emotional problems of their patients, provide the proper assistance when indicated, seek consultation when necessary, and refer the most serious and complicated problems to the appropriate mental health personnel. The Commission recommends that:

- **The Department of Health, Education, and Welfare provide funding for education in mental health principles, psychiatric evaluation, and treatment to primary health care givers and students, particularly physicians and nurses, preparing for work in primary health care.**

The development of a network of comprehensive mental health services requires that mental health personnel have a better understanding of the activities and contributions made by people working in the health, social service, and community support systems. People working in these fields also can benefit from a more complete understanding of mental health principles. The National Institute of Mental Health has for many years provided support for a limited number of pilot and experimental training programs. This capacity should be maintained. The Commission recommends that:

- **The Department of Health, Education, and Welfare:**
  a) **provide funding for selective projects designed to enhance the capability of personnel in mental health, health, social service, and community support systems to work more closely together; and**
  b) **facilitate joint funding where an educational institution proposes to meet more than one target problem in a single special training program.**

As the mental health care system evolves, additional personnel trained to perform highly specific tasks will be needed—personnel for case management and advocacy, for prevention, and for planning, evaluation, and administration. The Commission therefore recommends that:

- **The National Institute of Mental Health provide funding to special projects designed to develop programs in mental health administration, case management, and primary prevention.**

Curriculum Development

Throughout this Report we have made recommendations which require additional courses and curricula in basic educational programs. These same recommendations could also apply to the continuing education of those already working in the mental health field. In many instances, curricula and training materials for these priority areas are not adequate. Because this is a problem throughout the country, we believe it would be more efficient for the National Institute of Mental Health to develop and disseminate appropriate information. Therefore, the Commission recommends that:

- **The National Institute of Mental Health, through grants and contracts, fund the development of culturally relevant training materials and**

model continuing education programs for both mental health professionals and paraprofessionals.

- **The National Institute of Mental Health provide funds for developing and testing culturally relevant model curricula related to the nature and function of human service and community support systems for mental health specialists, paraprofessionals, and such community caregivers as primary care practitioners, clergy, and educators.**

Paraprofessionals

One of the major recent changes in mental health personnel has been the development of a large body of trained paraprofessionals. The social programs of the 1960's and 1970's initially funded the training and employment of poor, minority, or indigenous workers in human services as a way of creating jobs and of using the talents of people whose cultural closeness to those they served made them more understanding of their problems and better able to communicate with them. Many of these "new careerists" found employment in mental health agencies. A new kind of paraprofessional emerged with the development of community colleges and programs at the Associate of Arts level for human service workers, and there are now more than 200 such programs graduating 10,000 students a year.

The functions performed by paraprofessionals range from patient advocacy to counseling, from providing child care services to staffing halfway houses. No one can ignore the contribution they have made or the need to increase the effectiveness of that contribution. To better integrate paraprofessionals into the mental health personnel system, the Commission recommends that:

- **The National Institute of Mental Health accelerate its efforts to develop guidelines defining the various levels of paraprofessionals, specifying the activities they should perform, and the supervision they need.**

Needs Assessment for Personnel Planning

There is inadequate information and little agreement about the most appropriate activities which can be performed by the various categories of personnel, both professional and paraprofessional, or how many of each are needed to staff facilities. This makes difficult an assessment of national and local personnel needs, the designation of shortage areas, and the evaluation of efforts to meet these needs. To promote better planning and program direction, the Commission recommends that:

- **The National Institute of Mental Health develop a comprehensive mental health personnel information system.**
- **The National Institute of Mental Health, through contracts and grants, undertake studies to:**
  - **a) describe the services required by people with different types of mental or emotional problems;**
  - **b) develop models of function and qualifications for the staffing of mental health facilities and the provision of these services;[31] and**

c) **identify the ways in which the efficient utilization of personnel is impeded and suggest corrections.**[32]

Implementing the New Program

The redirection of Federal priorities we have proposed will require changes in current legislation.[33] It will also require a stable and adequate budget. Funds for research training are dealt with elsewhere in this Report. With regard to the development of personnel for service delivery, the Commission recommends that:

- **Funding for clinical and service manpower and training programs of the National Institute of Mental Health be increased to $85 million in fiscal year 1980, and in subsequent years be adjusted annually for inflation.**

The Commission realizes that this call for redirection occurs just as many academically based mental health training programs are feeling the effects of inflation, more stringent State budgets, and a reduction in funds from other Federal sources. It is entirely possible that some will find it difficult to maintain an adequate core training capacity. The Commission therefore recommends that:

- **The National Institute of Mental Health have the authority, for a period of no more than five years, to award distress grants for graduate professional education when it can be shown that a loss of current Federal funds would measurably alter the number of graduates or the quality of training.**

Protecting Basic Rights

The protection of human rights and the guarantee of freedom of choice are among the most basic principles of society. Mental health programs and services must not disregard these values. Each client or patient must have the maximum possible opportunity to choose the unique combination of services and objectives appropriate to his or her needs. This must include the option of preferring no services as well as the option of selecting particular services in preference to others.

Advocacy

We are keenly aware that even the best intentioned efforts to deliver services to mentally disabled persons have historically resulted in well-documented cases of exploitation and abuse. For this reason, an effective advocacy system must be created to protect the rights of all who receive services. The Developmentally Disabled Assistance and Bill of Rights Act of 1975 requires States to develop protection and advocacy systems for developmentally disabled persons as a condition of continued Federal funding for programs and services that assist this population. These systems, which now exist in all 50 States, include but are not limited to legal advocacy and function independently of service providers. Similar provisions should be made for advocacy on behalf of the mentally ill. Therefore, the Commission recommends:

- **The establishment of advocacy systems for the representation of mentally disabled individuals.[34] In adversary or judicial settings we recognize the importance of counsel to represent not only the mentally disabled client (or those acting in his or her behalf) but also the State or provider against which a claim is made.[35]**

Discrimination

Laws, regulations, and practices deprive mentally disabled people of equal entitlement and choice in securing Federal benefits, housing, jobs, education, health, and other services. Certain actions at the Federal level can help to end the needless discrimination against the mentally disabled in our society. Special attention must be given to children, the elderly, minorities, the involuntarily detained, the chronically mentally disabled, and prisoners—groups which are often at great disadvantage in coping with discriminatory practices. We believe periodic reviews of Federal programs will be particularly helpful in identifying and modifying unreasonable or discriminatory practices or requirements. Moreover, existing Federal programs in such diverse areas as housing, vocational rehabilitation, and aid for veterans and the elderly can be a valuable source of assistance for mentally disabled people. In many

instances, these resources can mean the difference between being in an institution and living in the community. The Commission therefore recommends that:

- **All Federal agencies enforce existing laws and regulations which prohibit discrimination against mentally disabled persons and seek to equalize opportunities for such individuals.**[36]
- **All Federal agencies review their statutes, regulations, and programs for instances of discrimination against mentally handicapped persons.**[37]
- **The Department of Health, Education, and Welfare vigorously implement the requirements of the Education for All Handicapped Children Act and formulate regulations to assist school districts to provide for the mental health needs of children and youth.**[38]

Commitment and Guardianship

Civil commitment is an intrusion on personal liberty and autonomy. Therefore, we believe that high priority should continue to be given to developing and adopting statutory language that describes, precisely and unambiguously, the types of conditions and behaviors that can lead to loss of personal liberty. There must also be increased procedural protections during the process of civil commitment.

We believe that high priority should also be given to improving the guardianship system. Because guardianship can lead to a deprivation of legal rights, it is a highly restrictive method of providing supervision and assistance to mentally disabled persons. It is therefore essential that guardianship laws be carefully tailored to avoid any unnecessary restrictions on the rights of individuals. Particular attention must be paid to increased procedural protections and to limiting guardianship to those activities in which a person has demonstrated an incapacity to act competently. The Commission recommends that:

- **Each State review its civil commitment and guardianship laws and revise them, if necessary, to incorporate increased procedural protections.**[39]
- **State guardianship laws provide for a system of limited guardianship in which rights are removed, and supervision is provided, for only those activities in which a person has demonstrated an incapacity to act competently.**[40]

The Rights of Those Receiving Care

There are strong legal, ethical, and social policy reasons for adopting the principles of a right to receive treatment, a right to receive treatment in the least restrictive setting, and a right to refuse treatment. While the Supreme Court has not ruled on whether there is a constitutional right to treatment (for mentally ill persons) or to habilitation (for mentally retarded persons), all involuntarily confined mental patients have a "constitutional right to receive such treatment as will give them a reasonable opportunity to be cured or to improve (their) mental condition."[41] To

fulfill this right, a State must provide treatment in a humane physical and psychological environment, qualified staff in sufficient numbers, and an individualized treatment plan for each patient. Mentally handicapped residents of institutions also have a constitutional right to protection from harm, physical intrusions, and psychological oppression or acts causing mental distress.[42]

The right to treatment in the least restrictive setting is inextricably tied to the adequacy of treatment and the specific needs of each individual. The criterion "least restrictive setting" refers to the objective of maintaining the greatest degree of freedom, self-determination, autonomy, dignity, and integrity of body, mind, and spirit for the individual while he or she participates in treatment or receives services. "Least restrictive setting" applies to both community and non-community-based programs.[43]

The right to refuse treatment is somewhat more complex and less developed. Consensus does not exist regarding this right. Its assertion rests upon a number of principles such as the right to maintain personal autonomy, the likelihood that treatment would be more effective if accepted voluntarily, and the need for "regulation" of treatment by protecting the individual from misuse of customary procedures. The right to refuse treatment is in some instances applied to specific forms of treatment which are particularly intrusive, for example, psychosurgery. The Commission's intent in enumerating the above principles is neither to validate nor invalidate them. We are of the opinion that this is a significant area which warrants careful consideration and informed deliberation in developing appropriate policies.

The Commission recommends that:

- **Each State review its mental health laws and revise them, if necessary, to ensure that they provide for:**
  - a) **a right to treatment/right to habilitation and to protection from harm for involuntarily confined mental patients and developmentally disabled individuals;**
  - b) **a right to treatment in the least restrictive setting;**
  - c) **a right to refuse treatment, with careful attention to the circumstances and procedures under which the right may be qualified; and**
  - d) **a right to due process when community placement is being considered.**[44]

To articulate these and other rights, the Commission recommends that:

- **Each State have a "Bill of Rights" for all mentally disabled persons, wherever they reside.**[45]

Confidentiality and Privacy

Confidential information in mental health records must be safeguarded if meaningful treatment is to take place and if mentally handicapped persons receiving

services are to be free from stigma, discrimination, and harm. Although confidentiality cannot be an absolute requirement, the Commission recommends that:

- **All recipients of Federal funds to provide mental health services be required to adhere to certain basic principles of confidentiality, and that other institutions and facilities be encouraged to follow this practice.**[46]

The gathering of research data is essential if we are to understand the variety of mental disorders and design programs of effective treatment and management. Biomedical and behavioral research frequently require access to patient and client records. Clear measures must be developed that permit the conduct of needed research while assuring the protection of individual privacy. While efforts are under way to develop these measures, we urge the Department of Health, Education, and Welfare to continue to clarify privacy and research issues. Our concerns about protecting the rights of people who become research subjects are discussed in the section entitled Expanding the Base of Knowledge under the heading Human Experimentation.

The Criminal Justice System

A high percentage of jail and prison inmates are mentally disabled. To make it possible for prisoners to receive the mental health services they need, or to continue in therapy initiated before incarceration, statutory changes should be made so that access to appropriate mental health services exists, and so that these services can be delivered on a voluntary basis with confidentiality comparable to that which exists in private care. Participation in treatment must be unrelated to release considerations if mental health services to prisoners are to be effective.[47] The Commission therefore recommends that:

- **Mentally disabled persons in detention or correctional institutions should have access to appropriate mental health services on a voluntary basis and such access should not be connected with release considerations.**[48]

Expanding the Base of Knowledge

Expanding our understanding of the functioning of the mind, the causes of mental and emotional illness, and the efficacy of various treatments is crucial to future progress in mental health. This is accomplished through research. Research is not an abstraction. It is a tool that can help to provide answers to questions about the causes, prevention, and treatment of mental illness.

Biological, psychological, and epidemiological research since World War II, much of it federally funded, has furthered our understanding of the nature and treatment of mental illness. Federal dollars have also supported social science research that has demonstrated the impact of situational stress and environmental conditions on emotional well-being. Behavioral and clinical research have contributed to important advances in the treatment of depression, schizophrenia, and behavior and learning disorders. Many of these advances can be traced to the financial investment the Nation made in mental health research between 1955 and 1969.

Since 1969, however, our national research capacity has undergone substantial erosion, and our investment in mental health research is now so low the development of new knowledge is jeopardized. If the Nation's research capacity is allowed to disintegrate, it will be far more difficult and costly to rebuild than to restore and improve it at the present time.

Restoring the Nation's Research Capacity

Our understanding of, and knowledge about, mental disorders did not increase just because Federal dollars were available, but because the dollars were allocated for the specific purpose of developing and sustaining a research capacity. Investigators from a wide range of disciplines, including both experienced senior investigators and promising young investigators, were supported. Institutions where research could be conducted received necessary assistance. Specialists in the management of scientific inquiry were developed to guide and direct these activities at both the policy and administrative levels.

While the number of new areas and problems requiring research has continued to grow, the combination of inflation and a Federal financial commitment that has remained at about the same level for the past ten years has resulted in a research dollar that can buy far less today than it could a decade ago. This threatens the research capacity that has been developed, and endangers the quality and the depth of research.

Neither science administrators in government nor researchers in the field can plan for sustained investigations. The duration of grant awards has been cut. The number of investigators supported has decreased. The size of the grants is being reduced routinely at the time they are approved. Ongoing projects are experiencing 10 to 15 percent cuts in their yearly budgets.

Reduced funding for research, training, and changes in policy, have impaired the ability to develop minority researchers, young scientists, and investigators in fields of study such as those associated with problems of racial minorities, childhood, adolescence, and the aging, as well as in the basic behavioral and brain sciences. Academic and research institutions and faculty have been forced to turn their energies to other areas, and new researchers are being discouraged from entering the field.[49]

Sufficient and stable funding of mental health research is a key element in generating and developing knowledge. Sufficient and stable funding are imperative if the three Institutes of the Alcohol, Drug Abuse, and Mental Health Administration are to continue to have vital and productive research programs.

The President's proposed budget for fiscal year 1979 calls for increases in funding for research at the National Institute of Mental Health, the National Institute on Alcohol Abuse and Alcoholism, and the National Institute on Drug Abuse. If Congress adopts these proposals, the first step will have been taken toward repairing the damage of the past decade. But it is only the first step. The Commission recommends that:

- **Priority be given to rebuilding our mental health research capacity over the next ten years and to investing an amount of money that is commensurate with the level of the problems associated with mental health, alcoholism, and drug abuse.**

To meet immediate needs in fiscal year 1980 so that promising research leads in the fields of mental health, alcoholism, and drug abuse can be developed and pursued, the Commission recommends that:

- **The National Institute of Mental Health research budget be increased by $30 million to a level of $165.4 million in fiscal year 1980.**[50]
- **The National Institute on Alcohol Abuse and Alcoholism research budget be increased by $9 million to a level of $30.2 million in fiscal year 1980.**[51]
- **The National Institute on Drug Abuse research budget be increased by $9 million to a level of $55 million in fiscal year 1980.**[52]

Approximately 88 percent of mental health and behavioral science research is federally supported.[53] Private sources fund about 4 percent, and State governments fund 8 percent. Although most State governments have either not invested in or are reducing the amount of money they invest in mental health research, we believe that they have a particularly pertinent role to play in the conduct of research. Research in the delivery of mental health services is one such area. The Commission recommends that:

- **The Administrator of the Alcohol, Drug Abuse, and Mental Health Administration develop guidelines for providing Federal incentives to stimulate increased State support of research activities in mental health and related areas.**

Despite the fact that one-third of Veterans' Administration hospital beds are occupied by patients with either mental or emotional disorders, only $3.5 million of the $100 million the Veterans' Administration spends on all research is directly allocated to research in mental illness. The Commission recommends that:

- **Veterans' Administration funds allocated to mental health research be increased to a level which more closely matches the amount of mental health services it provides.**

The training and support of research personnel are essential to the advancement of knowledge in mental health and the restoration of a strong research capacity. Today we find disillusionment, confusion, and an inability on the part of institutions, teachers, and trainees to plan for education and development. What is missing in many areas are skilled investigators to undertake the work that needs to be done. This is especially true of minority researchers. Because of the urgent need to restore our capacity to carry out research with well-trained investigators, the Commission recommends:

- **A review of the current manner in which the Federal government supports and trains research manpower, and a sensible increase over the next decade in that support to enhance our ability to train needed research personnel.**[54]
- **The National Institute of Mental Health research training budget be increased by $6.3 million to a level of $25 million in fiscal year 1980.**

Mechanisms to ensure accountability and relevancy in the use of public funds are essential to any responsive and responsible scientific enterprise.[55] Assessments of the peer review system over the past 30 years indicate that this method of judging research projects is sound. However, we need better data for the Alcohol, Drug Abuse, and Mental Health Administration to effectively monitor our present research and future research needs. We also need to gather research information throughout the government to better coordinate Federal research efforts and to better disseminate that information. The Commission recommends that:

- **A central data retrieval system which can be used for research management be created within the Alcohol, Drug Abuse, and Mental Health Administration, and a central system for cataloging mental health research conducted throughout the Federal government also be developed.**

- **Attention be given by the Alcohol, Drug Abuse, and Mental Health Administration to measures for increasing the flow of knowledge from investigator to investigator, and from researchers to practitioners and the public.**

Areas Requiring Special Attention

Long-term epidemiological and survey research are necessary to understand the incidence and scope of mental disorders in this country. The need for more precise demographic and socioeconomic data is urgent if we are to understand and meet the different needs which exist in our society. Data to determine the availability and utilization of services are also insufficient. Without such data it is difficult to assess needs or to plan for and deliver services. The Commission therefore recommends:

- **Immediate efforts to gather reliable data (including socioeconomic and demographic data) on the incidence of mental health problems and the utilization of mental health services. Particular attention should be paid to population groups within our society known to have special needs, such as children, adolescents, the aging, women, and racial and ethnic minorities.**
- **Increased research efforts designed to produce greater understanding of the needs and problems of people who are underserved or inappropriately served or who are at high risk for mental disorders.**[56]

We must enhance our understanding of how mental health services are currently provided and how they should be provided in the future. Research into the effectiveness of treatment, including valid patient outcome studies is necessary. We must also increase our knowledge about the kinds of personnel best suited to provide particular services, and the patient outcomes that result. There is a need for greater understanding of the effectiveness of support and treatment settings such as halfway houses, foster homes, rehabilitation centers, nursing homes, and day treatment programs. This involves a fuller understanding of the physical design of these treatment settings and how this relates to patient response. We should also increase our ability to evaluate newer treatment approaches such as nutrition therapy or less traditional treatment forms such as arts therapy. The financing of mental health facilities and services, the factors that influence service utilization, and manpower staffing patterns require attention and examination. The Commission recommends:

- **Expanded research on the ways mental health services are delivered and the policies affecting these services.**

Sociological, anthropological, biological, and psychological research, and research in the brain sciences must be encouraged if the promise of current work in these fields is to be realized. Learning more about the major mental disorders, the

process of learning, the factors that influence deviant behavior, and the addictive process is important and deserves higher priority for research funds. The knowledge gained from such efforts could form the basis for improving current treatment approaches. The Commission recommends:

- **Research directed toward understanding major mental illnesses, mental retardation, and basic psychological, sociological, biological, and developmental processes receive greater support and increased priority.**

Human Experimentation

We have discussed our concern about the confidentiality of patient and client records and the protection of individual privacy in the previous section under the heading, Confidentiality and Privacy.

The use of human subjects in biomedical and behavioral research also is a national concern. It involves not only patients, legal advocates, physicians, and the scientific community, but all who are concerned with ethics, human rights, and dignity.

The Commission recognizes the importance of research in advancing our knowledge about the causes, prevention, and cure or amelioration of mental disorders. There is no question that biomedical and behavioral research are necessary, but those who have been deprived of their personal liberty on the basis of alleged mental disability, or whose ability to give free and informed consent is otherwise questionable, should not bear the burden of scientific inquiry on behalf of society as a whole. We believe that continuing review and oversight are necessary to ensure that the difficult and important questions in this area are addressed.

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research has undertaken serious and steady examination of the problems posed by the use of human subjects in medical research, especially as it relates to the institutionalized mentally disabled. However, that Commission will soon end its work. The Commission recommends that:

- **An entity be created to replace the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. This entity should use a broad-based approach in evaluating policies developed by the current Commission and should address those questions still unanswered that relate to the protection of research subjects.**

A Strategy for Prevention

The Commission recognizes that mental health problems cannot be solved by providing treatment alone. Efforts to prevent problems before they occur are a necessary ingredient of a systematic approach to promoting mental health.

In the course of our deliberations we frequently heard people refer to three levels of prevention. Primary prevention was defined as any activity that attempts to eliminate the causes of mental disorder or disability; secondary prevention as activities involving the early detection and prompt treatment of disorders so that they do not become more serious; and tertiary prevention as the rehabilitation of individuals during or after an illness so that they will be able to live independently and with minimal permanent disability.

This Commission is concerned with preventing mental illness and emotional disturbance and with promoting the strengths, resources, and competencies of individuals, families, and communities. Our working definition of "prevention" embraces a broad range of activities which attempt to help individuals avoid becoming "patients."

The history of public health in the past century provides ample evidence that programs designed to prevent disease and disorder can be effective and economical. The mental health field has yet to use available knowledge in a comparable effort. Such efforts should be guided by the answers to six basic questions: (1) What groups of people are at high risk of developing mental illness or emotional disorder? (2) What factors contribute to the risk and what is the relative importance of each of these factors? (3) Can we effectively reduce or eliminate the most significant of these risk factors? (4) Does eliminating them effectively lower the rate of emotional disorder or mental illness? (5) If it does, are the costs of intervention justified by the benefits obtained? (6) Are the programs responsive to the principles governing both the rights of individuals and the rights of society?

With these six questions in mind, avenues that might be usefully pursued include: (a) reducing the stressful effects of life crisis experiences such as unemployment, retirement, bereavement, and marital disruption due to death or other circumstances, and (b) analyzing and understanding the nature of social environments, including those of hospitals and other institutions, so that, as an ultimate goal, environments may be created in which people achieve their full potential.[57] Although effective programs to reduce distress and emotional disorder can and should be developed for the entire life span, we believe that helping children must be the Nation's first priority in preventing mental disability.

Prenatal and Perinatal Care

Good care during the period of pregnancy and childbirth can prevent certain conditions that may later lead to mental disability and can detect others early enough for effective treatment. However, fully 30 percent of the pregnant women in

the United States currently receive no care during the first trimester of pregnancy. Abundant data indicate that severe maternal malnutrition retards fetal growth and that the combination of malnutrition and an impoverished environment inhibits proper mental development in infants. Genetic, biological, environmental, and motivational factors also represent potential threats to the newborn child's health and ability to thrive. To ensure good prenatal care and to minimize risk to the fetus of either physical or mental disability, the Commission recommends that:

- **Comprehensive prenatal and early infant care be available to all women, with special consideration given to school-age pregnant women and other high-risk groups.**[58]

Child Health Assessment and Developmental Review

The delivery of a biologically healthy infant does not guarantee that the child's psychological and social development will be smooth. It is vitally important to detect and attempt to correct at the earliest stages problems of physical, emotional, and cognitive development which can lead to emotional maladjustment and learning difficulties. The Commission recommends that:

- **A periodic, comprehensive, developmental assessment be available to all children, with consent of parents and with maximal parental involvement in all stages of the process.**

Provision should be made for children not eligible under existing publicly financed programs to participate. Mental health professionals should assist in training those who will perform the developmental assessment, and they should provide direct services where indicated.[59]

We are aware of the important relationship between health and mental health, and of the variety of Federal programs which can provide screening and follow-up care for the health and education of infants and children. In line with our belief that children's needs can be served most effectively by programs that provide comprehensive service, the Commission recommends that:

- **The Secretary of Health, Education, and Welfare review existing Federal programs that pertain to health and mental health services for infants and children and design a coordinated national plan to make available comprehensive services for all children.**[60]

Developmental Day Care Programs

With the growing number of working mothers—51 percent of the mothers of school-age children are employed, and many mothers work in order to meet

subsistence needs—many families urgently need more and better day care for their children. There are not enough programs available. A variety of child-care options should be explored.[61] Research has shown that child-care programs that focus on emotional and cognitive development can help to promote positive mental health. The Commission therefore recommends:

- **Increases in the number of Project Headstart and developmental day-care programs, so that within a reasonable period of time all children needing these and similar programs can have them available. Special attention should be paid to ensuring the inclusion of additional handicapped, rural, and migrant children. Such programs should be culturally acceptable to parents and the communities.[62]**

Foster Care and Out-of-Home Care for Children

When foster care and out-of-home placements last longer than one year, or when multiple placements occur, children are less likely to return to their natural parents. They are also more likely to develop significant emotional problems. Yet large numbers of children are placed without adequate prior evaluation or attempts at counseling and support for their families. Moreover, many children in placement receive no reevaluation or follow-up for extended periods of time.

Strong family support services and programs can prevent unnecessary and inappropriate foster care or other out-of-home placements and the difficulties which often result. Current Federal funding patterns often provide financial incentives for the removal of children from their homes but prevent them from being returned home or placed in other permanent living situations, including adoptive homes. This must be corrected. Efforts should also be taken to reduce the disproportionate number of minority children placed in out-of-home care. This is a particularly serious problem with American Indian children. We therefore reommmend that:

- **When children are candidates for out-of-home placement, there should be prior evaluation of the child and of the need for such placement. Family counseling and support should be made available.[63]**

A Center for Prevention

At present our efforts to prevent mental illness or to promote mental health are unstructured, unfocused, and uncoordinated. They command few dollars, limited personnel, and little interest at levels where resources are sufficient to achieve results. If we are to change this state of affairs, as we believe we must, the prevention of mental illness and the promotion of mental health must become a visible part of national policy.

To create visibility, there should be identifiable organizational components within Federal agencies that have direct responsibilities for mental health or whose programs clearly affect mental health concerns.[64] These components should be responsible for establishing priorities, developing programs, and advocating appro-

priate resources for the prevention of mental illness and emotional disorder. The programs which they sponsor should be aimed at high-risk populations and high-risk situations, limited to strategies where the prospects for successful intervention are greatest, and based on principles generally accepted in society. As a first step, the Commission recommends that:

- **A Center for Prevention be established in the National Institute of Mental Health.**[65]
- **Primary prevention be the major priority of this Center.**
- **$10 million be allocated during the first year with a funding level of no less than 10 percent of the National Institute of Mental Health budget within ten years, to support epidemiological, biomedical, behavioral, and clinical research aimed at prevention; to assess and evaluate existing programs of prevention; to replicate effective preventive programs, including those related to community support systems; and to engage in other appropriate activities.**

Improving Public Understanding

In this report we have noted the dramatic changes in the treatment of the mentally ill that have occurred during the past twenty-five years. We have highlighted the development of community care and the establishment of community mental health centers. We have described the trend toward moving people with chronic mental disabilities out of large State hospitals.

The shift from non-community to community-based care, while solving certain problems, has brought in its wake a number of new problems. Mentally ill and mentally retarded persons discharged from hospitals face difficulties in being accepted by people in their home communities. Too often, they return to find ignorance, prejudice, and fear of mental illness, discrimination, and social ostracism.

Few disagree with the principle that no individual who needs assistance should feel ashamed or embarrassed to seek or receive help. Yet people who have mental health problems, or who have had them in the past, often are discriminated against when they seek housing or employment, when they are involved in divorce or custody proceedings, when they are asked to serve on juries, and even when they attempt to vote.

These situations are usually discussed under the general heading of "public attitudes toward the mentally ill." But this is too general a thought, because it fails to take into account the fact that not all mental health problems are the same. Some people are, or have been, acutely ill. Others suffer a chronic, lingering disability and may elicit a different response than the person who is seen as having recovered or as capable of functioning "normally."

The misunderstanding and fear which still surround mental illness and mental retardation relate both to mental health services and to the people who are receiving or have received those services. More people now seek mental health care, and those who do often seek care sooner than they might have in the past. But many who need help do not seek it, and many who have received help do not admit it.

In large measure the greater understanding that has occurred is due to the development of community-based services. Many innovative mental health education and community information programs have been brought to our attention. We must continue to make people aware that mental health services are available in their communities so that people eventually are as willing to use mental health services as they are to use the emergency room in the local hospital.

The movement to treat in their own communities people who once would have been cared for in State mental hospitals has been a difficult idea for many individuals and communities to understand and accept. Surveys continue to show that a large portion of the public is both frightened and repelled by the notion of mental illness, even though it is less socially acceptable to say so. Old fears about State hospitals and the people who live in them abound. Rather than try to understand the differences among people with various forms of mental disability, many think only

in terms of the stereotypes seen on television. The need to increase public acceptance and understanding of the chronically disabled is a special issue. People with chronic mental disabilities are the most rejected and stigmatized of all, particularly because disproportionate numbers of them are also elderly, poor, or members of racial or ethnic minorities.

This Commission does not know how to end discrimination. We do know, however, that the quality of information available to the American people may help curb the fears and anxieties which lead to thoughtless, even cruel, responses to those who need help and understanding. In attempting to understand mental illness, it is worth remembering the observation made by the Joint Commission on Mental Illness and Health that unlike physical illness, mental illness tends to disturb and repel people rather than evoke their sympathy and desire to help.

We need better information about how people actually view mental illness and emotional problems. Many of the methods currently used to obtain such information were developed fifteen to twenty years ago when the mental health care system was very different. At that time most mental patients were confined to large State institutions. The response of communities to neighborhood mental health facilities was not an issue. In their daily lives, few citizens actually encountered people who were residents of mental hospitals, or who were struggling to overcome serious emotional problems. Thus attitudes were largely hypothetical and bore no relationship to first-hand experience. The questionnaires designed at that time, which still are in use today, do not make a sufficient attempt to distinguish between what people said and how they acted, or to measure how attitudes might have changed over time.

New methods for measuring community and individual attitudes must be devised; otherwise it will be impossible to assess the impact different community facilities have on individuals and neighborhoods; learn why people have certain feelings about those with mental illness and emotional problems; and learn how to develop a greater acceptance of mental patients and mental health services.

The media can play an important role in helping to eliminate stereotypes and in presenting accurate information to the public. The media have already made positive efforts in this direction. But, because of the impact television has on the development of attitudes in children, we are concerned with its emphasis on violent acts without appropriate explanation or interpretation. The sporadic violence of so-called "mentally ill killers" as depicted in stories and dramas is more a device of fiction than a fact of life. Patients with serious psychological disorders are more likely to be withdrawn, apathetic, and fearful. We do not deny that some mentally ill people are violent, but the image of the mentally ill person as essentially a violent person is erroneous.

Clearly, there is a need for more accurate portrayals of mentally and emotionally troubled people in documentaries and in drama. There is a similar need for accurate fictional and journalistic portrayals of the everyday lives and problems of people who struggle with a whole range of mental and emotional problems.

This Commission believes that mental health practitioners, volunteers, and others who seek to help the mentally ill or to represent their concerns must constantly reassess their own attitudes toward those they seek to help and toward each other. They could contribute to public understanding by providing a more accurate description of the nature and variety of services and assistance they offer and a more candid account of their own expectations and limitations.

When this Commission first was formed, we received a letter which said in part:

"Mental health . . . affects every one of us—depression, marital problems, drug and alcohol-related problems, inability to cope as the result of a death or serious accident, low self-esteem, social maladjustment problems, dealing with delinquent children, and so many more situations."

The letter was a reminder that almost all Americans encounter these problems, either themselves, or in their families, or among their neighbors and friends. Nevertheless, the fear and misunderstanding of mental illness and emotional problems are deeply ingrained in our society. Our task now is to begin to understand that the causes of mental health problems are as varied as their manifestations. Some are physical. Some are emotional. Some are rooted in social and environmental conditions. Most are a complex combination of these and other factors, some of which are unknown.

In this way we may begin to understand that none of us is immune from mental illness or emotional problems, and that the fear, the anxiety, and even the anger we feel about people who suffer these problems may merely reflect some of our own deepest fears and anxieties.[66]

Annotations

Annotations

Findings and Assessments

[1] See Report of the Task Panel on the Nature and Scope of the Problems, President's Commission on Mental Health.

[2] See Report of the Task Panel on the Nature and Scope of the Problems, President's Commission on Mental Health.

Community Supports

[3] Personal and community supports are not a substitute for formal mental health services. Our recommendation for the development of personal and community supports should not be used to justify public policies which would withhold from various communities and individuals the resources they need to obtain professional and formal institutional services.

[4] Most of the early "alternative" services were started by indigenous helpers—professionals and non-professionals—in direct response to the specialized physical and emotional needs of disaffected young people in the mid to late 1960's. They offered emergency medical care, a safe place during a bad drug trip, or short-term housing as alternatives to the traditional health, mental health, and social service facilities these young people found threatening, demeaning, or unresponsive. Advocacy for the social changes that would make individual change more possible was seen as an inevitable complement to the direct service work they performed.

More recently, "alternative" services have expanded and diversified in response to their clients' changing needs. Drop-in centers work with the families and teachers of the teenagers who come to them. Runaway houses have opened long-term residences and foster care programs for those young people who cannot return home or would otherwise be institutionalized. Free clinics and hotlines have provided specialized counseling services for other and older groups. The alternative service model has been adopted by some human resource programs which have identified new community needs.

Community groups that have been providing "alternative" services should be included on agency review panels (from which, because of their lack of credentials or established connections, they are almost always excluded) and on the State or local boards which ultimately decide where funds are used. Notices of available Federal and State grants should be routinely sent to these alternative services.

[5] The effort we recommend should be developed and located within the National Institute of Mental Health and could include the following types of activities:

a) **coordination of existing Department of Health, Education, and Welfare programs for community support systems with the National Institute of Mental Health for the purpose of pooling information and technical assistance as requested by the community;**
b) **exchanges of information among lay community groups and mental health professionals about model, ongoing community support programs;**
c) **development, through grants and contracts, of demonstration programs with an evaluation component that can identify effective ways to establish linkages between community mental health services and community support systems; and**
d) **development of research initiatives on the efficacy of social networks as adjuncts to mental health service delivery systems, and on the effects of informal and formal community support systems on the utilization of health and mental health services.**

Among the activities which should be developed at the State and local level are:

a) **the inclusion within the Health Systems Agency plan and the State Health Plan of material which takes into account the role of community support systems;**
b) **the examination by community mental health service programs of their own program plans in terms of their complementing or supplementing local natural helping networks, with particular attention to the needs of families and to the social and cultural factors of the communities they serve;**
c) **the involvement of community people in this process of needs assessment and ongoing program evaluation;**
d) **the development of inservice training activities in community mental health service programs about the support systems indigenous to their community; and**
e) **the participation in these programs of caregivers from the support systems so that mental health professionals and community caregivers can learn from each other.**

A Responsive Service System

[6] The seven additional services include services to children; services to the elderly; screening services for courts and other public agencies considering individuals for referral to a State facility; follow-up care for persons discharged from a mental health facility; transitional services for people who might otherwise require

inpatient care; alcoholism and alcohol abuse services; and drug addiction and drug abuse services.

[7] The funds requested are for new starts under the Federal grant program we have proposed. These figures do not include funds for continuing these programs after the first year or funds for meeting prior obligations to community mental health centers funded under previous authorization.

[8] To maintain the availability of a comprehensive range of services for populations served by federally funded community mental health centers, the Commission specifically recommends:

- **Special Federal funding for community mental health centers which have reached, or are reaching, the end of their eight-year Federal funding period.**

Such funding should not exceed 30 percent of the eighth year of the Federal community mental health centers grant. Centers should be required to match this on a 25 percent to 75 percent basis. The money should be specifically designated to support service activities essential to a comprehensive system of care but which are rarely reimbursable. The program should be reviewed no later than five years after its inception.

[9] While States currently have the authority to designate catchment areas, Federal regulations set forth a principle that these areas should include between 75,000 and 200,000 people. Regulations do allow a waiver of these population requirements by the Secretary of Health, Education, and Welfare. Unfortunately, the waiver is rarely used, and these arbitrary population limits, which fail sufficiently to take into account natural communities, create unnecessary barriers for both those who need and those who provide care. We are convinced of the importance of developing catchment areas which reflect natural communities and neighborhoods and which do not encompass huge geographic areas. The Commission recommends that:

- **The Secretary of Health, Education, and Welfare encourage a waiver of catchment area population requirements where it would best serve the needs of natural communities and those requiring services.**

[10] There are instances in which a particular service may be highly specialized or very costly or where the volume of demand may be so limited that one catchment area cannot support it. Examples might include a residential treatment center for adolescents, an inpatient unit for children, or a bilingual and bicultural program for a minority population. Under such circumstances, cross catchment program sharing should be encouraged. The Commission recommends that:

- **The Department of Health, Education, and Welfare propose any necessary legislation to facilitate cross catchment area planning and delivery of high cost and/or specialized services.**

[11] The responsiveness of community-based programs to the needs of local areas is greatest where governance and advisory board arrangements provide assurance of adequate citizen/consumer representation. While this requirement should exist for all federally funded mental health programs, we feel that laws, guidelines, and regulations should be flexible enough to accommodate differing circumstances or different communities. Rural areas, for example, often need greater flexibility in terms of the number of meetings because board members must travel long distances. Greater flexibility also is required to allow organizations such as community groups, voluntary hospitals, medical schools, and group practices or Health Maintenance Organizations to sponsor federally supported mental health programs. The Commission recommends that:

- **The National Institute of Mental Health seek changes in current legislation to permit differences in board and governance arrangements so they may properly reflect existing local circumstances.**

[12] To come closer to the goal of informed citizen involvement in the governance of mental health programs, we must provide board members with enough information to perform effectively. The Commission recommends that:

- **The National Institute of Mental Health strengthen its capacity to respond to requests for information and technical assistance for the members of mental health advisory/governance boards to deal with problems related to the planning and delivery of mental health care.**

[13] The working alliance must be strengthened between the health and mental health systems. As initial steps, the Commission recommends:

- **Funding by the Department of Health, Education, and Welfare of a limited number of research projects to assess integrated general health care and mental health care services.**
- **Requiring community mental health centers and community mental health service programs, where appropriate, to establish cooperative working arrangements with health care settings.**

These arrangements should allow for:

a) **mental health personnel to provide direct care and treatment in the health care setting to patients with emotional disorders whose problems exceed the skills of non-psychiatric health care practitioners;**
b) **consultation directed toward altering behavioral patterns that increase the risk of physical illness;**

c) **collaborative treatment with non-psychiatric health care practitioners for those patients with combined physical and mental illness; and**

d) **training non-psychiatric physicians and other health care personnel to enhance their skills in the treatment of patients with relatively mild emotional disorders.**

[14] The State and Federal governments must work together to find new jobs for displaced employees who cannot be transferred to jobs in community facilities. Even when jobs are available, steps must be taken to provide continuity in pension benefits. We must also be willing to provide discharged workers with the retirement security they expected. Consistent with the congressional intent expressed in Section 314(d) of the Public Health Service Act, the Commission recommends that:

- **Relevant Federal agencies review the feasibility of providing priority in hiring at Veterans' Administration hospitals and other Federal installations for former employees of State mental hospitals, and review the feasibility of amending Federal personnel laws to permit the option of payment into State pension funds for State workers who are hired by the Federal government.**

The Commission would also encourage States to amend State law to permit former mental hospital employees and their new employers to make payments into State pension funds or to purchase an annuity with the actuarial value of the State pension. These steps would make employee pension rights truly portable.

[15] Performance contracts are a way to clearly define mutual expectations, responsibilities, and commitments. Both parties spell out what they intend to accomplish, how it will be done, at what pace, and at what cost. After goals have been mutually agreed upon, variations in means and mechanisms to achieve these goals are allowed for, but end points remain constant. In this instance, the end points of the performance contract relate to the phasing down and closing of State hospitals; upgrading the quality of care provided patients occupying the residual beds; retraining and placing employees dislocated by the phase-down process; and developing comprehensive systems of alternatives to hospitalization and aftercare services.

The contract amount should provide enough Federal dollars (including Medicare, Medicaid, Title XX, and Comprehensive Employment and Training Act monies) to permit institutional care which not only meets certification standards but also reflects the greater needs of those who remain in State hospitals. Contract monies would also be available for the development of aftercare programs and facilities as well as for programs and facilities to serve as alternatives to hospitalization. They should also support employee training and job placement efforts.

Provision should be made for the Federal contribution to remain constant throughout the contract period. Savings of State and Federal dollars realized through meeting performance expectations related to the phase-down of State institutions should be applied to the development of community services for the long-term

patient and to improving the quality of care of patients who continue to use the services provided in State hospitals. Neither Federal nor State governments should be permitted to reduce their level of support for mental health services not covered by the contract.

[16] An alternative for making funds available to support the objectives of this program could be a mechanism such as joint funded grants, as authorized by the Joint Funding and Simplification Act of 1976.

[17] As noted, chronically mentally ill persons in the community often are in no position to organize or manage the services they need. For such people, a case manager can play an important role, and the Commission recommends that:

- **State mental health authorities, in consultation with local authorities, designate an agency in each geographic service area to assume responsibility for assisting the chronically mentally ill of that area.**
- **The agency assigned this responsibility employ trained case managers, either directly or by contract with another agency. The development of linkages with community support systems should be a recognized function of both the agency and the case manager.**

This agency would be responsible for ensuring that clinical care is provided and continuity of services assured. Where possible, the case manager should have liaison responsibilities with the State hospital inpatient unit. In this way, case management can begin before a person is returned to the community. When trained case managers are not available, the responsible agency should provide or contract for the necessary training.

[18] The transfer from less restrictive residential settings should be based upon a determination by the State Mental Health Authority and the designated Title XX authority of a person's being inappropriately placed in a medical facility. Transfer should be to residences in the community affiliated with appropriate service entities.

If the ceiling on Title XX expenditures in each State were lifted by an amount determined by the number of inappropriate medical placements supported with Title XIX payments, the State could then transfer these patients into non-medical community facilities, with a corresponding decrease in Medicaid payments. The incremental cost of Title XX would be shared by the State and Federal governments on the same basis as Title XX payments. On a per patient basis, the transfer would be accomplished without a net additional cost. The new Title XX budget ceiling would be maintained in subsequent years.

[19] In 1972, Professional Standards Review Organizations were mandated by Federal law. All services covered by Medicare, Medicaid, and Maternal and Child Health Programs will eventually be reviewed by Professional Standards Review Organizations to assure that they are necessary, appropriate, and of adequate quality.

Professional Standards Review Organizations, however, are physician-controlled organizations. This has been a matter of concern to non-physician professionals in general and to the mental health field in particular. Mental health care in most organized settings is multidisciplinary, and the Commission believes that the involvement of psychologists, nurses, and social workers, along with paraprofessionals knowledgeable about community resources, should be required.

[20] While the processes of accreditation and licensure are intended to establish minimal standards of excellence, many have commented on the multitude of inspections which are required. These include State and local building inspectors, State licensing reviews, and Medicare and Medicaid site visits for a number of different programs. State, Federal, and local reviewers may be inspecting a facility more than half the working days in a year.

[21] To facilitate coordinated health and mental health planning at the regional and State levels, the Commission recommends:

- **Inclusion in the Health Systems Agency plan of a mental health component developed by local and regional mental health authorities with assistance of representative ethnic, professional, and consumer citizen advisory groups.**
- **Delegation by the health planning authority to the State Mental Health Authority of the responsibility for aggregating mental health plans and preparing the mental health component of the State Health Plan. Funds for such activities must be provided to the State Mental Health Authority.**
- **Designation of monies for mental health planning in the budget of each Health Systems Agency.**

[22] To assure adequate representation of mental health interests in the general health planning process, the Commission recommends:

- **Reservation of at least two places on the National Health Planning Council for representatives of mental health interests.**
- **A guarantee of 25 percent representation for mental health interests on the boards of Health Systems Agencies and on the State Health Coordinating Council.**
- **A requirement that State Mental Health Advisory Boards review and comment upon the mental health component of the State Health Plan. This report of the State Mental Health Advisory Board would be submitted to the State Health Coordinating Council.**

[23] To facilitate the resolution of differences between the health and mental health sections concerning priorities and directions, the Commission recommends that:

- **The State Health Plan be subject to the approval of the governor, with provision made for the resolution of differences between the State Health Coordinating Council and the Mental Health Advisory Board prior to submission of such plans to the Secretary of the Department of Health, Education, and Welfare.**

[24] As a first step toward coordinating planning among the mental health, social services, vocational rehabilitation, housing, and education systems, the Commission recommends that:

- **Guidelines for the preparation of the State Comprehensive Mental Health Services Plan be amended to require the inclusion and publication of health, social service, housing, rehabilitation, and education components in the plan.**

New Directions for Personnel

[25] This program should follow the model established by the Health Professions Educational Assistance Act of 1976. Funds are provided for tuition and living expenses. The recipient is required to spend a year of service in a designated shortage area for each year of assistance received. The minimum period of service is two years. An individual who fails to comply with the service provision is liable for three times the amount received, plus interest, payable within one year of default.

No one should be required to give more than four years mandatory service in a shortage area, regardless of the number of years of support for training.

[26] Funds should be awarded to universities with the provisos that a substantial amount of clinical training take place in programs and settings providing care to underserved populations; clinical work in such programs and settings be supervised by university faculty, funds be provided for the training costs associated with this; and content on the culture, needs, values, and special problems of minorities, bilingual populations, and the special needs of women be included as an integral part of training.

Because these new programs will be built upon and added to the basic core educational curriculum, multi-year funding will be necessary for their development and continued viability. The Commission urges that these programs, where possible, stress multidisciplinary training as a way of promoting collaboration among the professions and increasing understanding of and respect for the unique competencies of each discipline.

As an additional step in improving training for work in underserved areas, the Commission recommends that:

- **The National Institute of Mental Health establish a limited number of postgraduate teaching fellowships designed to improve the training capacity of facilities in underserved areas and increase the number of educators with special skill and competence in the problems encountered in working in rural areas and public facilities.**

[27] Actions that might be taken include general revision and upgrading of salary schedules, and higher salaries for professionals in shortage areas or facilities; development of career ladders; sabbatical leave for rural practitioners; use of visiting teachers and consultants; and promotion of continuing education, either in agency programs or through the use of released time.

In addition, State mental hospitals should consider the increased use of contract mechanisms with the private sector, or the employment of physician assistants, child health associates, and nurse practitioners for the provision of medical services to patients. As a way of coordinating these activities, the States should establish comprehensive personnel development plans as integral components of their mental health service plans.

[28] The Commission urges that priority for placement of psychiatrists fulfilling a service obligation in the National Health Service Corps be given to facilities which are inadequately staffed with these physicians. These include State and county mental hospitals and community mental health centers.

[29] Fewer than 2 percent of all psychiatrists are Black, and data on other minorities are difficult to interpret because of the large number of foreign medical graduates of Asian or South American origin. A recent survey by the American Psychological Association estimates that of all doctoral level health service providers in psychology, 0.9 percent are Black, 0.7 percent Asian, 0.4 percent Hispanic, and 0.1 percent American Indian. Social work and nursing are more representative of the population, with an estimated 15 percent of National Association of Social Workers members and 7 percent of nurses belonging to the American Nurses Association Division of Psychiatric and Mental Health Nursing coming from minority groups.

Educational data, however, show that the number of Black psychiatry residents has been increasing, and they now comprise 3.4 percent of the total. Slightly over 6 percent of the Ph.D's awarded in 1976 in psychology were to minority students, and over 12 percent of first year graduate students were from these groups. In social work, 24 percent of the social workers who received bachelor's degrees and 17 percent of those receiving master's degrees in 1976 were minority students, as were 18 percent of the graduates from basic registered nurse programs in 1975.

[30] A special need exists to expand our capacity to understand and deal with the emotional problems associated with the aging process. Few programs exist which coordinate treatment, research, and training in this area. To remedy this lack, the Commission recommends that:

- **The Department of Health, Education, and Welfare fund a number of centers on the mental health of the elderly where graduate and postgraduate students in all the major professions can be trained.**

[31] The models developed by the National Institute of Mental Health should be flexible enough to account for the difference in the nature of facilities and case loads and the considerable overlap in capability and function among the mental health disciplines, and yet be firm enough to assure quality of care.

[32] Particular attention should be paid to salary and civil service structures, procedures for evaluating credentials, and the ways in which present and projected methods of financing of services influence the staffing patterns of facilities and the utilization and geographic distribution of manpower.

[33] We recommend that Section 303 of the Public Health Service Act be revised to authorize the awarding of both grants and contracts by the National Institute of Mental Health for training mental health personnel and research and planning activities in this area, with flexibility of funds. Specific authority should be given for

the awarding of scholarships and loans to students, with payback provisions in the National Health Service Corps similar to those in the Health Professions Educational Assistance Act of 1976. The development of an adequate information system, within the Alcohol, Drug Abuse, and Mental Health Administration, should be considered an integral part of the program activities.

PROTECTING BASIC RIGHTS

[34] The development of structural mechanisms, while necessary, cannot by itself be effective in offering appropriate assistance to mentally disabled persons. Other important sources of support are the efforts of legal aid, legal services, and public defender programs, and the private bar at large, to represent mentally handicapped persons in their contacts with the mental disability system. The Commission therefore recommends:

- **Increased activities by the Legal Services Corporation to represent mentally handicapped persons more adequately and effectively.**

[35] At least three reasons support the need for counsel in representing the State or provider:

—If the State or provider is represented by an administrative officer instead of a lawyer, a judge may tend to redress the balance by assuming the role of the party not represented by counsel.

—In the absence of counsel for the State a number of ethical problems may arise for the patient's advocate. For example, he or she may feel ambivalence about revealing evidence of his or her client's dangerousness or lack of competency.

—Availability of counsel to the State may serve a useful "preventive law" function.

Mental health professionals, administrators, and patients will benefit from an appreciation of the limits on their actions and options imposed by the law; and legal advice offered to mental health professionals and administrators by their own counsel is less likely to be regarded as threatening or antagonistic to their interests.

[36] Section 504 of the Rehabilitation Act of 1973 prohibits discrimination on the basis of mental or physical handicap in federally assisted programs. This law was enacted more than four years ago. If other Federal agencies would follow the example of the Department of Health, Education, and Welfare and promptly issue program-specific regulations to implement Section 504, discriminatory practices in education, employment, housing, and other public and private services could be significantly curtailed.

[37] The list of Federal benefit programs potentially available to mentally handicapped persons is impressive—for example, Supplemental Security Income, Medicare, Medicaid, Social Services; Old Age and Survivors and Disability Insurance; food stamps; Civilian Health and Medical Program Uniform Services (Department of Defense) and Veterans' Administration entitlements; specialized services such as vocational rehabilitation, maternal and child health services, family planning services, and nutritional programs for the elderly. Unfortunately, mentally handicapped persons often do not receive the full benefits because of their handicap

or because of the locale where the service is provided. These types of discrimination are compounded by restrictive interpretations of "disability" or "illness," by failure to disseminate information about the existence of resources or eligibility for benefits, and by jurisdictional confusions.

[38] This legislation emphasizes the concept of "mainstreaming" and the provision of services to severely disabled children. "Mainstreaming" does not mean that all children, regardless of the nature or severity of their handicaps, must immediately be assigned to regular classroom situations. It does require, however, that teachers be prepared to deal in a normal classroom setting with children who exhibit various types and degrees of handicapping conditions.

The mandate to educate all handicapped children requires that traditional notions of what constitutes a program of education, or even of special education, be revised. For the most disabled individuals, education may consist of training in basic self-help, social or behavioral skills, or addressing severe emotional problems before academic instruction in the usual sense can be considered. Federal regulations would, in many instances, highlight specific steps which could be taken to implement the law and achieve its goals.

Wherever possible, mentally disabled children who are institutionalized should be provided with an appropriate education in a community setting in order to help normalize their lives and reduce stigma. This would include those in mental hospitals and State schools for the mentally retarded as well as mentally handicapped children in various correctional or juvenile facilities. The considerations that lead to institutionalization of children often have nothing to do with educational needs. They should not be allowed to interfere with a child's right to an appropriate education in the least restrictive and most normal setting feasible.

[39] The Commission recommends that:

- **Model legislation incorporate increased procedural protections including, but not limited to:**
  - **a) initial screening of potential commitment cases by mental health agencies;**
  - **b) a prompt commitment hearing preceded by adequate notice to interested parties;**
  - **c) the right to retained or assigned counsel;**
  - **d) the right to a retained or assigned independent mental health evaluator;**
  - **e) a transcript of the proceedings;**
  - **f) application of the principle of the least restrictive alternative;**
  - **g) a relatively stringent standard of proof (for example: "clear and convincing evidence");**
  - **h) durational limits on confinement (with the ability of a court to specify a period of confinement, short of the statutory maximum); and**
  - **i) the right to an expedited appeal.**

At the commitment hearing, the rules of evidence shall apply, and the respondent should have the right to wear his or her own clothing, to present

evidence, and to subpoena and cross-examine witnesses. The petitioner should also be represented by counsel fluent in the petitioner's primary language.

The Commission also recommends that:

- **Procedural protections in guardianship laws should include but not be limited to:**
  - **a) written and oral notice;**
  - **b) the right to be present at proceedings;**
  - **c) appointment of counsel;**
  - **d) a "clear and convincing evidence" standard as the burden of proof;**
  - **e) a comprehensive evaluation of functional abilities conducted by trained personnel; and**
  - **f) a judicial hearing that employs those procedural standards used in civil actions in the courts of any given State.**

[40] Only about one-third of State guardianship laws make provision for limiting the power of guardianship to reflect accurately the abilities and disabilities of those persons who are under guardianship. Because many mentally handicapped persons need only a limited degree of supervision, laws which provide only for full guardianship inevitably restrict important legal rights without justification.

[41] Wyatt v. Stickney. 325 F. Supp. 781, 784 (M.D. Ala. 1971) (subsequent history omitted).

[42] A number of States already provide a statutory right to treatment or protection from harm either for persons committed to State mental institutions or for all persons residing in such institutions. These include Florida, Wisconsin, and New Jersey. The Florida statute sets forth as the "policy of the State" that it "shall not deny treatment for mental illness to any person" and that "no services shall be delayed because of inability to pay." The Wisconsin statute states that all patients "have a right to a humane psychological and physical environment within the hospital facilities." The New Jersey statute provides that "every service for persons with developmental disabilities offered by any facility shall be designed to maximize the developmental potential of such persons and shall be provided in a humane manner."

[43] Numerous courts have held that governmental action which infringes on personal liberty must be limited to the extent necessary to achieve the governmental objective. This principle has been repeatedly applied in the mental health field.

[44] Because of rightful concern for the civil liberties of those involuntarily hospitalized, due process procedures have been increasingly required by the States. The goal is to ensure that hospitalization is in the individual's or society's best interests. In contrast, the same degree of concern is rarely shown for the individual's or society's interest in returning the patient to the community. This is especially true for those who have had long hospitalizations and lack a receptive family in the community. Some disabled individuals are released to living and care arrangements that are inadequate for their level of functioning, even though they themselves may have objected to such placements. These occurrences, popularly referred to as "dumping," only further debilitate and stigmatize the chronically mentally disabled.

In recognition of the fact that returning the patient to the community may involve complex clinical and legal issues, the Commission recommends that:

- **Due process be ensured for those individuals being considered for placement in the community against their wishes.**

[45] Such a bill of rights should include at least seven basic components:

a) **a statement that all mentally handicapped persons are entitled to the specified rights;**
b) **a statement that rights cannot be abridged solely because of a person's handicap or because a person is being treated (whether voluntarily or involuntarily);**
c) **a declaration of the right to treatment, the right to refuse treatment, the right to dignity, privacy, and confidentiality of personal records, the right to a humane physical and psychological environment, and the right to the least restrictive alternative setting for treatment;**
d) **a statement of other, enumerated, fundamental rights which may not be abridged or limited;**
e) **a statement of other specified rights which may be altered or limited only under specific, limited circumstances;**
f) **an enforcement provision; and**
g) **a statement that handicapped persons retain the right to enforce their rights through habeas corpus and all other common law or statutory remedies.**

State laws establishing rights of mentally handicapped persons should be printed in the natural or dominant language of the persons to whom they apply and prominently displayed in a manner appropriate to the setting where services are received. This would include but not be limited to posting rights in all inpatient wards of hospitals, nursing homes, and other 24-hour care facilities; living areas of community residential programs; and in common areas of day care and partial hospitalization programs, outpatient clinics, mental health centers, and emergency treatment units, whether for the mentally ill or the mentally retarded. The specified rights should be incorporated into all staff training and staff orientation programs as well as in educational programs directed to patients, staff, families, and the general public. A copy of the rights should be given to each patient and should be read or explained in an easily understandable way and in the persons' natural or "dominant" language.

[46] The Commission believes Federal and State laws should recognize the following basic principles of confidentiality:

—Patients should have access to their own mental health records in accord with rules and regulations which protect the rights of the patient, other individuals and organizations who have contributed to the record, and providers.

—Confidentiality of mental health information should be strictly maintained by all persons who have contact with such information.

—Consent forms for release of information concerning patients' histories should be limited to particular items of information in their records relevant to the specific inquiry posed by third parties who have a legitimate need for such information.

—Employers' questions to job applicants and employees should be related to objective functioning skills directly relevant to the specific job for which the applicant or employee is being considered.

—Patients should remain anonymous when third-party insurers use peer review or other similar mechanisms to evaluate the need and appropriateness of treatment.

[47] Many mentally handicapped persons in detention or correctional institutions who need mental health services could be helped by basic physical improvements in prisons. We therefore believe that the Department of Justice should place a high priority on allocating Federal grant funds for the improvement of prison living conditions and the provision of appropriate health and mental health services.

[48] When a mentally handicapped prisoner desires transfer to a mental hospital and mental health and prison authorities concur that such treatment would be beneficial, a number of unnecessary legal hurdles now serve as barriers to effective mental health care. In some jurisdictions, for example, voluntary admission for prisoners is simply unavailable.

A number of court decisions have held that because of the possibility of mistake, stigma, and a lengthier period of confinement, a prisoner who is to be involuntarily transferred to a mental hospital should first be granted a civil commitment-type hearing. Despite such constitutionally grounded decisions, some jurisdictions continue to make such transfers unilaterally and to regard them as equivalents of administrative "placement and classification" decisions. All jurisdictions seeking involuntary hospitalization for prisoners should provide safeguards equivalent to those accorded non-prisoners undergoing civil commitment. The Commission therefore recommends that:

- **Each State should enact a prison-hospital transfer law with procedures to protect those prisoners who become patients.**

Expanding the Base of Knowledge

[49] Only about 20 percent of the Alcohol, Drug Abuse, and Mental Health Administration's (ADAMHA) current budget goes to research, compared to 50 percent ten to fifteen years ago. While other health research and Federal health expenditures have grown dramatically, ADAMHA's actual buying power has declined by about 20 percent since 1969, and that of the National Institute of Mental Health (NIMH) by 35 percent. The length of funded grants has decreased over the past decade. In 1968, 80 percent of approved grants requesting four-year funding received it; only 33 percent do today. In 1978, 28 cents of every dollar spent on research will go for indirect costs and not for research itself. In 1969, NIMH funded 85 percent of those grants approved as having merit. By 1976, this number was approximately 55 percent. Not only have approved NIMH grant applications been funded by 10 to 15 percent less than the amount requested, many ongoing projects have been cut annually by an additional 10 to 15 percent.

[50] Despite the decline in research capacity, advances have been made in a number of important areas. These range from service delivery, treatment efficacy, and the impact of social and cultural factors to brain and behavioral processes and the understanding of child psychopathology and the mental health of the aged. Many of the next steps to be taken are known, and a number of areas of research

require added attention. The proposed FY 1979 research budget increase, contained in our Preliminary Report, represents the first positive step toward repairing the damage of the past decade. However, it only brings NIMH back to 75 percent of its 1969 purchasing potential. The recommended $30 million increase for FY 1980 would bring the Institute up to 85 percent.

[51] Of the three ADAMHA Institutes, the National Institute on Alcohol Abuse and Alcoholism (NIAAA) spends the smallest percentage of its total budget on research, 9 percent. Until recently, alcoholism research needs have been eclipsed by service priorities. The funding base of NIAAA research must be raised in order to encourage and build needed research manpower and to develop the knowledge needed to decrease the high incidence and prevalence of alcoholism and the resultant mortality and morbidity.

[52] This recommended increase for FY 1980 in combination with that proposed for FY 1979 will have a major impact on restoring the National Institute on Drug Abuse's (NIDA) capacity to advance the understanding of drug abuse prevention and treatment. It should be recognized that NIDA has had no research budget increase since 1974. In addition, NIDA was forced to close its intramural research facility. The move to a new location must be accomplished as rapidly as possible.

[53] At the Federal level, ADAMHA accounts for about 53 percent of the mental health research budget, and the Veterans' Administration for 3 percent. The remaining 44 percent is spent by other agencies and departments such as the National Science Foundation, and agencies and institutes within the Department of Health, Education, and Welfare. This latter group includes the Office of Education, the Administration on Aging, and Institutes located in the National Institutes of Health, such as the National Institute on Child Health and Human Development, the National Institute on Neurological and Communicative Disorders and Stroke, and the National Institute on Aging. We did not conduct an extensive review of the mental health-related research supported by these agencies, but it is clear that an examination of this research should be undertaken.

[54] Research training is an ongoing process. Our capacity to carry out high quality research depends heavily on well trained, active investigators. For this process to continue, we must foster training programs in several areas that have a shortage of researchers, as well as undertake measures to augment existing training programs. There is a clear need for increased manpower in epidemiology, clinical investigations, childhood psychopathology, aging, science-based clinical psychology, evaluation, and mental health services and policy research.

Most research manpower development is regulated by the National Research Service Awards Act. The implementation of this Act results in the underfunding of institutions. It defines research training content and mechanisms too rigidly. The question of whether its "pay back" philosophy may serve to discourage talented individuals from going into research training by tying them to an uncertain commitment upon completion of training should be explored. The present mandatory proportioning of pre- and post-doctoral awards is unrealistic and does not take differentiated science needs into account. The Committee on a Study of National Needs for Biomedical and Behavioral Research Personnel of the National Research Council of the National Academy of Sciences is studying this matter. In addition, changes should be made so that investigators from various fields can be trained in a multi-disciplinary approach at both pre- and post-doctoral levels. Finally, more flexible regulations allowing greater pre-doctoral support are urgently needed if we

are to respond to the need for developing minority researchers in all areas of science.

Greater flexibility in these regulations will also help us to meet the need for science-based clinical psychology investigators and investigators in childhood disorders, psychopathology, and the problems of aging. We suggest the following proposals:

—There should be developed within ADAMHA a program patterned after the Minority Access to Research Careers program of the National Institutes of Health (NIH).

—A careful review and assessment of the programs and consequences of the National Research Service Awards Act should be undertaken to determine ways to increase the capacity and the quality of research manpower.

—ADAMHA's research scientist award programs should be enhanced by giving them a high priority for resource allocations, by removing eligibility restrictions, and by changing the restrictions on periods of support.

—NIMH should initiate medical scientist training programs (M.D.-Ph.D.) to develop investigators with the multiple skills needed for mental health and mental illness research.

[55] While we have not been able to pinpoint all structural and administrative issues, we have identified three ways to enhance efficient management and coordination within and among the three ADAMHA Institutes and to provide accurate and timely assessments of our knowledge and our ability to research a given problem:

a) the establishment of Research Analysis and Policy Units within ADAMHA and its component Institutes to provide assessments of the research portfolio. These units would help the agency administrator and the institute directors to arrive at rational and balanced research priorities;

b) to achieve more objectivity, accountability, and credibility in selecting and managing research projects, a Division of Research Grants which would separate merit review of grants from their program management should be established within ADAMHA in a manner appropriately adapted to the missions of the Institutes;

c) to speed the pace by which meritorious research can begin, one percent of appropriated research dollars should be allocated to a Director's discretionary fund to support new research opportunities, after sound advice and review.

[56] A host of factors—biological, educational, socio-cultural, and others—influence the mental health of children and adolescents. We need to increase our understanding of these factors and their effect on both mental disorders and the normal developmental processes of young people. The supply of trained investigators for this task is inadequate, as is budgetary support of investigative programs. The elderly also require a special focus. The incidence of psychopathology in general, and depression in particular, rises with age. It is urgent that research addressed to the problems of aging move forward. Research must also begin to address a wide range of issues relating to women. Other research should be undertaken to understand the needs and problems of underserved populations, such as Asian Americans, Blacks, Hispanic Americans, and Native Americans. These groups represent about 17 percent of the United States population and suffer disproportion-

ately from the alienation and fear, depression and anger which accompany prejudice, discrimination, and poverty.

Developmental life crises, stress situations, crime and delinquency, and the mental health of population groups with special problems, such as veterans (especially Vietnam veterans) and migrant and seasonal farmworkers, should also be studied.

A Strategy for Prevention

[57] Other areas of study might include:

a) promoting maternal-infant bonding and facilitating positive maternal perceptions of the newborn child;
b) developing systematic educational programs in such preventively oriented areas as education for marriage and prenatal parent education;
c) utilizing existing program knowledge and developing further programs for building competencies in young children;
d) dealing with the mental health needs of children hospitalized for physical conditions; and
e) promoting the development of helping networks and mutual support groups that deal preventively with both everyday crises and extraordinary crisis situations.

[58] In addition to health care, additional services should include screening programs offering genetic counseling, amniocentesis, and selective and optional terminations of pregnancy where medically indicated, and food supplementation regimens for pregnant women medically diagnosed as at-risk nutritionally. In all instances, prenatal, health, and counseling services should respect ethnic and sociocultural preferences and beliefs.

Parent education programs to junior high school and high school students should be continued and expanded. Separate and distinct from sex education, parent education programs should be designed to help adolescents know themselves physically and psychologically, to offer direct work experience in day care centers or other children's services, and to make available day care services for the children of teenage parents, enabling the parents to remain in school.

[59] The Early and Periodic Screening, Diagnosis and Treatment Program of Title XIX (Medicaid) of the Social Security Act does not include the availability of treatment and service provisions to cover mental illness, mental retardation, and developmental disability when these conditions are diagnosed. The proposed Child Health Assessment Program should mandate that these services be available. As a general rule, a dollar for follow-up services should be allocated for every dollar allocated for screening.

[60] These programs include those funded under Titles IV, V, XVI, XIX, and XX of the Social Security Act; the Education for All Handicapped Children Act; Title II of the Economic Opportunity Act of 1964 (Head Start and Follow Through); the Child Nutrition Act; and the National School Lunch Act.

[61] Two-thirds of the children estimated to need day care are of school age. According to the Bureau of the Census, there are nearly two million "latch-key" children who come home to an empty house each day. It seems more than coincidental that the rise in the number of "latch-key" children has been

accompanied by an increase in school vandalism, adolescent alcoholism, and juvenile participation in serious crime (now 45 percent of the serious crime committed). To provide more care for school-age children, pre- and post-school recreational, remedial, and enrichment programs should be continued and expanded for children in need of these services.

For older children, some schools are experimenting with a model whereby children check in with a counselor and report where they are going, but do not actually have to remain on school premises. We urge that employers and school systems in the private as well as the public sector extend school hours and use school buildings to provide recreational, remedial, and enrichment programs for children by voluntary or community organizations after the regular school day until 5 or 6:00 p.m. to coincide with the working schedules of parents.

[62] The Commission specifically recommends that the Administration for Children, Youth, and Families in the Department of Health, Education, and Welfare:

- **Design a flexible program that supports a variety of child care arrangements, with adequate provision for evaluation.**

The Commission also recommends that:

- **The Department of Health, Education, and Welfare support programs to recruit and train caretakers at all educational levels and from a wide variety of age, ethnic, and socio-cultural groups.**

[63] In placing children in out-of-home care, the rights, obligations, and responsibilities of both the parents and the agency should be specified at the time of placement. The child's progress and efforts to work with the biological family should be reviewed every six months. A dispositional hearing to determine whether the child will be returned home, referred for termination of parental rights and subsequent adoptive placement, or, in special cases, placed in long-term foster care should be held within 18 months of placement.

[64] The National Institute of Mental Health and its parent agency, the Alcohol, Drug Abuse, and Mental Health Administration in the Department of Health, Education, and Welfare, have direct responsibilities for mental health. Agencies whose programs clearly affect mental health concerns include the National Institutes of Health, the Office of Human Development Services, and the Office of Education within the Department of Health, Education, and Welfare, and the Departments of Labor and Housing and Urban Development.

[65] The Center to be located in the National Institute of Mental Health should be the lead Federal agency in prevention of mental and emotional dysfunction. As such, it would have convening authority to initiate, stimulate, and coordinate all such Federal activities. Organizational mechanisms to develop prevention programs should be established in other Federal agencies as well.

Because a national program also requires program development throughout the States and linkages between Federal and State activities, State-level Offices of

Prevention should be responsible for maintaining an overview of the State preventive efforts in order to encourage the development of prevention programs wherever indicated. We therefore urge the establishment by each State of a locus of responsibility for the prevention of mental and emotional disorders.

Improving Public Understanding

[66] To achieve the objectives we have stated, the Commission recommends that:

- **Research be conducted to design instruments that measure public attitudes toward people with various types and degrees of mental illness and toward mental health services and facilities. These instruments should measure attitudes related to the actual behavior of people being surveyed. They should be used to identify and develop public education programs and other techniques as well as to assess the effectiveness of current public service announcements in creating a climate of community understanding and acceptance of mental patients and the facilities and services they need.**
- **A Collaborative Media Resources Center be established which would be operated by a consortium of mental health professional associations and voluntary groups and which would include the participation of patients or former patients. Information developed by the proposed Center should take into account cultural and linguistic differences in the population.**
- **The Department of Health, Education, and Welfare establish a task force, composed of members from the public and private sectors and including former patients from various segments of society, to propose and stimulate new approaches for reducing discrimination against the mentally disabled and the mentally retarded and toward increasing public understanding in these areas.**

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Report to the President from The President's Commission on Mental Health

Volume I

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Individual reports submitted to the Commission by the task panels, as well as the Report of the Joint Study on Mental Health Services, may be purchased from the National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Road, Springfield, Virginia 22161.

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