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ABSTRACT

This document contains the text of a Senate hearing on barriers to health care for the chronically mentally ill. Senator Orrin Hatch discusses the history of health care for the mentally ill and the changing role of the federal government, and Senator Edward Kennedy summarizes legislation initiated for the chronically mentally ill. The superintendent of the Mental Health Institute in Independence, Iowa, a professor of psychiatry at the University of Wisconsin, and a chronically mentally ill person testify on behalf of the National Mental Health Association. Testimonies are also included from the director of the National Institute of Mental Health; an officer of the National Alliance for the Mentally Ill; the executive director of the Davis County Mental Health Center in Farmington, Utah; and the director of the Institute of Psychiatry and Human Behavior at the University of Maryland. Two witnesses discuss their children's mental illnesses. Prepared statements are included from an executive officer of the American Psychological Association and from the president of the International Association of Psychosocial Rehabilitation. Witnesses discuss their concerns regarding the barriers to care for persons with chronic mental illness and explore the roles of family, community mental health programs, and state and federal governments in providing care. Prepared statements and additional question-and-answer materials are included. (NRB)

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BARRIERS TO HEALTH CARE FOR THE MENTALLY ILL

HEARING

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE

NINETY-NINTH CONGRESS

FIRST SESSION

ON

OVERSIGHT ON VARIOUS BARRIERS TO HEALTH CARE FOR THE CHRONICALLY MENTALLY ILL

OCTOBER 9, 1985

Printed for the use of the Committee on Labor and Human Resources

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WEDNESDAY, OCTOBER 9, 1985

ADDITIONAL MATERIAL

BARRIERS TO HEALTH CARE

WEDNESDAY, OCTOBER 9, 1985

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The committee met, pursuant to notice, at 10 a.m., in room SD-430, Dirksen Senate Office Building, Senator Orrin Hatch, (chairman) presiding.

Present: Senators Hatch, Kennedy, and Grassley.

OPENING STATEMENT OF SENATOR HATCH

The CHAIRMAN. We are happy to call this hearing to order, and I apologize for being late.

This hearing is being conducted to consider the issue of barriers to health care.

Our focus today is on the chronically mentally ill. This being National Mental Health Awareness Week, it is only fitting that we take this opportunity to learn about the needs of the chronically mentally ill. These are the people who are probably least able to care for themselves.

For too long, many of the chronically mentally ill were inappropriately locked away in dismal institutions, forgotten, ignored, and mistreated. It has taken a long time for a more enlightened attitude to evolve within our national community. Today, we recognize that with appropriate care and support, many of our Nation's chronically ill can be active, and they can be contributing members of society.

There is mounting hope that through research we will be able to improve treatment and eventually prevent chronic mental illness altogether. That would be a wonderful day.

Historically, development of care for the chronically mentally ill has been dramatized by sharp contrasts. In the past two centuries, this kind of care has been provided primarily in large institutions. Yet our country has a long history of providing compassionate care at the local level. At the start of the 19th century, there was a movement to provide care for the chronically mentally ill in small centers organized around the family. At the turn of the century, the development of psychoanalysis led to the movement of providing care in small centers associated with universities. And finally, in the 1960's, the advent of modern psychiatric medications brought about a movement to deinstitutionalize the chronically mentally ill and to care for them in community health centers.

With each of these movements, there initially followed some impressive cure rates. Yet in each case, time also brought with it overly centralized decisionmaking which retarded clinical progress.

Finally, in 1981, Congress enacted the alcohol, drug abuse and mental health services block grant transferring outpatient services for the mentally ill to the States. This legislation, which I was pleased to sponsor, and which I was pleased to have Senator Kennedy give his great expertise to, gave priority to treatment for the chronically mentally ill. In addition, the bill cut out much of the Federal regulatory barbed wire which prevented community mental health centers from effectively treating the chronically mentally ill.

A GAO report in 1984 discovered, in fact, that States were becoming more able to treat more patients with chronic mental illness, further proving that States and localities are best able to determine their own needs.

As illustration, I would just cite my own home State of Utah, which is aggressively trying to provide support for the chronically mentally ill. With State, local, and Federal governments working together, Utah has been developing a statewide community mental health service delivery system available to 95 percent of those in need. The goal has been to provide appropriate care in the least restrictive environment, combined with the support of the family. This has enabled my home State to provide compassionate care for the chronically mentally ill.

Today, we will hear from the people who provide many of these services for the chronically mentally ill. We will also hear from individuals with chronically mentally ill family members. Community efforts to help families have developed and been successful, and I am one of the many to become active advocates for the Community Support Program. This small program provides support to States to coordinate housing services, health treatment programs, vocational programs and other such services. In 1984, this committee unanimously supported statutory authority for this program. In addition, its scope was expanded to include seriously disturbed children and chronically mentally ill elderly.

Finally, the Federal Government does have a role to play in encouraging State, local community and family efforts to help the chronically mentally ill. When I first came here, I have to admit I had some very stark opinions about how things should run, and I have had to change them. And I have to acknowledge that I have had a great deal of help from members of this committee, and in particular Senator Kennedy, who I think really has been a major leader in the field of health in this country for many years.

The role of the Federal Government, I think, does center around the continued search for methods to prevent and cure mental illness. Over the last 3 years, we have spent over one-half billion dollars for basic research on mental illness. From 1983 to 1985 there has been almost a 25 percent increase in this effort.

I agree with Jennifer Jones-Simon's statement that "increased knowledge alone offers the real hope of a future free of much of the pain, suffering and the attendant human and dollar cost of mental illness." I strongly believe that continued research for treatment and disease prevention provide the best long-term solutions.

As noted earlier, this is Mental Illness Awareness Week. For the third consecutive year a resolution has been sponsored by our distinguished colleague on the Labor and Human Resources Committee, Senator Quayle, declaring the second week in October "Mental Illness Awareness Week." This commemoration focuses public attention on the incidence, causes and treatment of the mentally ill and on exciting advances in research. By designating this week, we can focus attention throughout our country on the need for further education and commitment.

Activities on local and State levels are being held. In addition, here on Capitol Hill a symposium sponsored by the American Psychiatric Association will be held following this hearing, highlighting the most recent advances in mental illness treatment and research.

Today's hearing may become a prelude to early legislative action to further help families with members suffering from mental illness.

I look forward to hearing the testimony of today's witnesses—Mrs. Norma Lagomarsino, the wife of Congressman Robert Lagomarsino; Dr. Shervert Frazier, the Director of the National Institute of Mental Health; Mrs. Ginny Krumdieck. And I am also pleased to welcome our own Dr. Russell Williams from Utah, whom I have a tremendous regard for; Dr. John Talbott, Dr. Bhasker Dave, Dr. Leonard Stein, and Mr. Joseph Rogers.

So, we have a very good set of panels here today, and I am looking forward to listening to all of you.

I will now turn to Senator Kennedy. I am very grateful to have you here, Ted.

Senator KENNEDY. Thank you very much, Mr. Chairman. I want to express my appreciation to you for holding this hearing. I believe that it is the first hearings we have held on this subject matter for a number of years, and I think it is a reflection of your own deep concern and commitment for the problems that we are facing in so many of our communities, in trying to think of some new approaches to deal with the challenges that we face.

You have mentioned the association of this committee with the problems of mental health, as well as retardation and other health needs, that have been longstanding since the early part of the 1960's when we passed the first community mental health legislation and then again in 1980, when we passed important legislation dealing with the mental health issues. That was altered and changed after the 1980 elections, to the alcohol, drug abuse, and mental health block grants.

It is entirely appropriate that we have an opportunity to revisit this subject matter, given the kinds of changes we have seen in the field. We have seen the institutionalized population drop from about half a million down to perhaps 125,000. We would like to think that those people who have been deinstitutionalized are out in the communities, and that there is a community-based system, but quite frankly, there is not.

I think all of us are increasingly conscious of the fact that there are increasing numbers of individuals, homeless people, who are in great need of care and attention.

We have to try and review what the problems are and how we can best deal with them.

I am mindful, Mr. Chairman, that we are spending a good deal of resources on these problems—over $8 billion in Federal, State and local funds. But I think it is quite appropriate that we evaluate whether we are spending that money effectively. It is my conclusion that we are not. It is not just the question of the current resources, but it is how we are going to allocate those resources in an effective way to try and do the job.

Today, I think we are going to have impressive testimony about the importance of community-based systems. We will hear about some of the problems that we are facing in terms of the funding priorities and underfunding of community care and how resources can be allocated in a way which will address the important human needs that we face in this area.

Finally, I just want to express appreciation because, Mr. Chairman, in many respects these are the neediest people in our society, the most vulnerable people in our society, and I think we can have an important impact in terms of meeting some of their very significant needs, and I welcome the opportunity to work with you and other members of the committee in attempting to do so.

I would like to ask that my complete statement be filed in the record.

The CHAIRMAN. Without objection.

[The prepared statement of Senator Kennedy and a summary of his legislation follow:]

from the office of
Senator Edward M. Kennedy
of Massachusetts

STATEMENT OF SENATOR EDWARD M. KENNEDY
AT HEARING ON IMPROVING SERVICES TO THE CHRONICALLY MENTALLY ILL
OCTOBER 9, 1985

The last three decades have witnessed both great hope and cruel disappointment for the chronically mentally ill. Beginning in the early 1950's, the development of psychotropic drugs produced a true revolution in the treatment of this population. For the first time, medicine could significantly improve the ability of the chronically mentally ill to function in society and could reduce the pain, anguish, and delusions produced by mental disease.

With these new developments, there was widespread awareness that long-term confinement of the mentally ill in large institutions should be replaced by a system of community care. As President Kennedy stated in his 1963 State of the Union message, "The abandonment of the mentally ill to the grim mercy of custodial institutions too often inflicts on them a needless cruelty which this nation should not endure."

Advances in psychotropic medicine and other social changes did lead to a remarkable decline in the number of patients confined to mental hospitals. Between 1955 and today, the number of patients resident in public mental hospitals declined from over half a million to 120,000.

But, the removal of patients from mental hospitals was not matched by the growth of the community-based system of care that President Kennedy envisioned. Instead, the deinstitutionalized mentally ill too often live in single room occupancy hotels or board and care homes. With no services, no treatment, no integration into the larger society, they are condemned to spend their days staring at the walls or wandering the streets.

And the mentally ill who live in board and care homes or single room occupancy hotels are not the most unfortunate members of this population. On an average day in this great country of ours, there are between 125,000 and 250,000 chronically mentally ill individuals without any home at all. It is a sad commentary on our society that one can walk a block from The White House and find confused, hallucinating, mentally ill people, talking to themselves, dressed in rags, and sleeping on grates even during the bitterest winter days.

And, if the experience of the chronically mentally ill were not tragic enough, the experience of their families is just as sad. There can be few experiences as shattering for a parent as having to cope with the reality of a mentally ill son or daughter; to have to cope with that reality and to know that society is providing no meaningful assistance either to your child or to you must be almost more than a person can bear.

The situation faced by our chronically mentally ill citizens would be heartrending if it were unavoidable. But, the sad state of so many chronically mentally ill Americans is not unavoidable--it is disgraceful.

We know how to care for the mentally ill in the community. We know how to assure that each mentally ill individual can live in humane conditions. We know how to provide the care and treatment that will allow each mentally ill individual to come closer to his or her potential.

But, despite this knowledge, far too many states and communities have failed to provide the care for the chronically mentally ill that constitutes simple justice. And, the Federal government has failed to provide the leadership that is its responsibility.

I recently introduced legislation that would assure the provision of the comprehensive system of community care that the chronically mentally ill need and deserve. Such a system of care has been shown to reduce hospitalization for mental illness as much as 50% and to bring great benefit to the victims of these cruel diseases.

I look forward to the comments today of our expert witnesses on this legislation,on the problems the chronically mentally ill face, and on the effective things that government, communities, and families can do to help.

As we begin this hearing, I am reminded of a letter written by the great artist, Vincent Van Gogh shortly before his suicide at the age of 37. He wrote, "Oh, if I could have worked without this cursed disease, what things I might have done."

Let it not be said of us at future hearings that we unnecessarily deprived the mentally ill of the opportunities for self-development and happiness that all our citizens deserve or that we deprived our society of the contributions that another Van Gogh, similarly afflicted, might have made had his life not been cut short.

SUMMARY OF KENNEDY LEGISLATION
INITIATIVE FOR THE CHRONICALLY MENTALLY ILL

The Kennedy initiative is designed to create an effective, community-based system of care for the chronically mentally ill. Well designed community-based systems of care have been shown to reduce hospitalization rates from chronic mental illness as much as 50 percent as well as reducing the misery, isolation, and hopelessness associated with chronic mental illness.

The key features of an effective community-based system of care include:

--case management, so that someone is resonsible for seeing that each chronically mentally individual gets the care and support services he needs;

--a program of habilitation and rehabilitation, which would provide services to the chronically mentally ill appropriate for their level of functioning and responsive to their individual needs. Needed activities can range from regular social contact to vocational training, supervised work, or assistance in obtaining and keeping competitive employment;

--medical treatment, which would provide treatment ranging in intensity from day hospitalization to a periodic appointment with a psychiatrist to check on and adjust medication;

--assistance to families, who often provide the front-line care for the mentally ill in the community and have too often been left to cope with the severe strains of mental illness without any assistance from the society at large; and

--housing services, ranging from halfway houses with staff in residence providing continuous supervision to largely independent living.

The legislative changes the Kennedy initiative would make to achieve the objective of a comprehensive, community-based system of care for the chronically mentally ill include:

ALCOHOL, DRUG ABUSE AND MENTAL HEALTH (ADAMHA) BLOCK GRANT CHANGES

--To qualify for ADAMHA block grant funds, a State must develop and implement a comprehensive mental health plan for the chronically mentally ill. The plan must cover all mental health funding sources in the State--including Medicaid, State and local funds, and private insurance funds, not just the relatively small PHS funding.

--The plan must provide for the establishment and implementation of an organized, community-based system of care for the chronically mentally ill as defined by the Secretary of HHS in regulations. The plan must include provision of case management services for all chronically mentally ill individuals receiving public funds. The plan must include a progrom of outreach to the homeless mentally ill. Once the plan is accepted by the Secretary, progress toward achieving plan goals and objectives is a condition for continued ADAMHA block grant funding.

--The plan must be developed with the assistance of a broad-based advisory board including advocates for the mentally ill as well as public and private agencies dealing with the mentally ill.

--An additional $10 million is provided in the first year after adoption of the legislation to assist States in developing their comprehensive plan. An additional $50 million per year is provided in subsequent years to assist in plan implementation.

--A demonstration program of project grants to agencies developing and implementing methods of serving the homeless chronically mentally ill is established.

MEDICAID CHANGES

Under current law, Medicaid is not clearly available--except through a waiver process that only a few States have applied for--to fund the social services, habilitative, and rehabilitative services the chronically mentally ill need in the community. By contrast, Medicaid support is fully available for care in State mental institutions for chronically mentally ill individuals who are 20 or younger, or 65 or older. Medicaid is available without any age limit for chronically mentally ill individuals in skilled nursing facilities or intermediate care facilities, so long as those facilities are not institutions primarily for the treatment of mentall illness. And, Medicaid is available without any Federal limits for care in the psychiatric ward of a general hospital. The institutional bias in current Medicaid rules has been an important factor in inhibiting State development of a true continuum of care for the chronically mentally ill.

The initiative would make the following changes to improve Medicaid's contribution to the community care of the chronically mentally ill and to reduce the unnecessary institutionalization that Medicaid often pays for.

--States would be required to provide case management services under Medicaid for the chronically mentally ill.

--States would be required to provide community and home-based care under Medicaid for Medicaid-eligible chronically mentally ill. Community and home-based care would include the essential elements of a service system for the chronically mentally ill, such as day treatment activities, habilitiation, and rehabilitation services, staff and service costs of supervised living arrangements, foster care, vocational and prevocational services, respite care, day care and day hospitalization, mental health clinic services, crisis intervention servicesk, and counseling and assistance for families of the chronically mentally ill.

--To assure that services would be provided cost-effectively, States would be allowed to waive normal Medicaid rules and arrange for the provision of care on a contractual or capitated basis.

--The Secretary of HHS would be required to provide technical assistance to States in fulfilling these Medicaid plan requirements.

--Skilled nursing facilities and intermediate care facilities treating chronically mentally ill patients would be required to provide appropriate services. Currently, States place Medicaid-eligible chronically mentally ill patients in these facilities to get Medicaid reimbursement, but, because Medicaid will not reimburse care provided in an institution for the treatment of mental disease, appropriate staffing and services are not required.

--The Secretary would be authorized to fund demonstrations in up to five States or regions within States of the delivery of services on a capitated basis with a single entry point.

--Hospitals receiving Medicaid reimbursement would be required to have a written discharge planning arrangement to assure that any chronically mentally ill patients discharged after a spell of illness would have a program in place assuring receipt of case-management and appropriate community services.

--A maintenance of effort requirement would be established to assure that States did not simply replace current State funded services in the community with Medicaid-funded services.

SSI CHANGES

Many chronically mentally ill individuals are eligible for Supplemental Security Income because of their disability. SSI eligibility also usually asssures Medicaid eligibility. Some features of the current SSI program, however, need to be changed in order to provide appropriate service to the chronically mentally ill, who differ from other disabled populations in that their disability is often episodic.

--Institutionalization for more than thirty days normally means the loss of SSI payments. In situations where the chronically mentally ill person relies on SSI income to maintain a residence, a short-term spell of illness can thus mean that the patient will be homeless when he is discharged. This legislation would continue enough of the SSI income to maintain a residence when the period of institutionalization is expected to be for less than six months.

--Delay in SSI eligibility can often be disastrous for a chronically mentally ill individual. This legislation would provide for presumptive SSI eligibility--including Medicaid eligibility--for chronically mentally individuals who are about to be discharged from an institution, who are at imminent risk or institutionalization, or who are homeless and willing to participate in a plan of care.

--Persons resident in public institutions are not eligible for SSI under current rules. This limits State flexibility to establish half-way houses and other transitional living facilities. This proposal would allow SSI eligibility in such facilities.

--Persons who exceed a certain level of earnings, called the SGA test--are no longer eligible for SSI, no matter how disabled they remain from the medical point of view. This is not an important problem from the income support standpoint, but, since Medicaid eligibility and SSI are linked, a chronically mentally ill individual who has been able to work may lose the very medical and support services that have made his working possible. This legislation would remove the disincentive to work inherent in this rule by allowing continuance of Medicaid coverage for three years after the SGA test is exceeded by a chronically mentally ill person.

--Permanent liberalization of the SGA test. To remove a disincentive to enter the work force on the part of SSI eligible individuals, the SGA standard was liberalized in 1980 for a three year period. The liberalization was recently extended until 1987. This legislation would make the change permanent.

HOUSING LAW CHANGES

One of the major changes facing the chronically mentally ill and agencies serving them is achieving decent housing, particularly housing that can be used for transitional living facilities. Changes made by this legislation to assist with the problem include:

--Revise the Urban Housing Program to allow State mental health authorities or other private non-profit or public agencies designated by the State to claim vacant HUD properties for use for transitional living. An authorization of $5 million the first year would be established and of $15 million in each of the two subsequent years.

--Establish a set-aside of Section 202 subsidized housing as provided in HR 1 to make it easier to develop housing for the handicapped, including the chronically mentally ill.

--Establish a new program of housing vouchers tailored especially for the chronically mentally ill. Costs would be shared on a 50-50 basis between the State and Federal governments. The authorization would be $5 million in the first year, $15 million in the second year, and $25 million in the third year.

The CHAIRMAN. I want to thank you, Senator Kennedy. And again, I stress that I have long admired, and especially over these last number of years since I have been chairman of this committee, the work that Senator Kennedy has done in the area of health. And frankly, he has taught me a great deal, and I personally want to just express that publicly to him. We still have some differences with regard to how to do things, but on the other hand, I believe he has been a tremendous leader in this area, and he deserves a lot of credit for it.

So thank you, Ted. I appreciate it.

Now, I know that Senator Kennedy has to leave because of diplomatic protocol to attend the joint session of Congress today. I know he wants to be here throughout this hearing, but he also knows our speaker today at the joint session from Singapore and would be remiss if he did not go.

So his heart will be with us, as I think he lives up to his formal responsibilities to be there.

Now I am pleased to welcome our witnesses on the first panel, but first I would like to share with you, however, a note from Jennifer Jones-Simon, who was to appear as our opening witness.

She states, "Dear Mr. Chairman, Due to the circumstances of my husband's illness, I find at the last minute that I am unable to appear in person before your committee on October 9. I hope that the enclosed brief statement can be incorporated into the record of this important hearing

"Thank you for this opportunity.

"Sincerely, Jennifer Jones-Simon."

So I would, without objection, place her testimony in the record, and I want to personally express and publicly express to Mrs. Simon our gratefulness for her willingness to testify, and I regret to learn of Mr. Simon's setback. I hope it is only temporary.

[The prepared statement of Jennifer Jones-Simon follows:]

Mr. Chairman:

My name is Jennifer Jones Simon. For years I have been trying to learn all that I can about mental illness. I want to speak briefly to you today about something which perhaps the other witnesses may not.

I have been exposed to a wide variety of systems for the care of the mentally ill, both here and abroad. I have become deeply convinced that these problems can be solved. That long term and expensive care is not inevitable, and that we are on the verge of being able to save wasted lives as well as cutting the staggering economic burden.

What I have come to believe it will take to do this is a deep commitment to a sustained national investment in scientific research. For the first time in history scientists have developed the technologies by which significant answers can be found.

Until we have a more fundamental understanding of the brain, we can not emerge from an era largely dedicated to treating symptoms to an era of prevention and cure. We need to pinpoint both genetic and environmental factors. Biochemical imbalances must be investigated. Until we get down to some understanding of mental processes at the molecular level we will not have the capacity to adequately treat mental illness with appropriate therapies.

The knowledge is within reach. New technologies allow us to see the structure and the function of the brain. Scientists can begin to correlate specific behaviors with specific chemical changes. What is most encouraging is to see our young scientists ready and willing to commit their lives and their careers to studying such mysterious and tragic problems as schizophrenia and other devastating mental disorders.

The dollars we put into research are <u>invested</u>, and should pay for themselves many times over.

Dr. Richard Wyatt, a respected Federal scientist, has calculated that between 1969 and 1985, the use of lithium in the treatment of manic-depressive illness resulted in savings of more than $6 billion dollars that otherwise would have been spent on clinical care and lost through the effects of this illness. The ten-year savings is more than double the amount this country has put into mental health research from 1948 until today.

We as a Nation cannot afford not to invest in research on the major mental disorders. It has been estimated that if research now underway were to result, by 1998, in a 10 percent annual reduction in the direct and indirect costs of schizophrenia, treatments and care costs over the subsequent decade would be reduced by $180 billion dollars.

The needs of the severely mentally ill and their families are enormous and urgent. Your resolve to respond to those needs is commendable and I urge you to focus on eliminating obstacles to improved treatment and better care. Beyond that, my special plea today is that we make the vitally important investments in research. Increased knowledge alone offers the real hope of a future free of much of the pain, suffering and the attendant human and dollar cost of mental illness.

Thank you.

Jennifer Jones Simon

The Chairman. I am very pleased to welcome Mrs. Norma Lagomarsino, the wife of Congressman Bob Lagomarsino. I want to thank you for sharing your personal experiences with the committee.

I would also like to welcome Dr Shervert Frazier, the Director of the National Institute of Mental Health.

And finally, I would like to welcome Mrs. Ginny Krumdieck, the second vice president of the National Alliance for the Mentally Ill.

I would also like to announce that a very dear person to all of us is in the audience, Mrs. Domenici, Pete Domenici's wife. We are very grateful to have you here, and we appreciate the work that you do and the concern that you have in this area.

We will begin with you, Mrs Lagomarsino. Now, I have to limit each of you to 5 minutes because of the many activities of this whole day. In starting half an hour late, my time is even more limited. So please do not be offended; we are going to put all statements in the record as though they were fully delivered. We appreciate that, and if you will tolerate me on that score, I would appreciate it.

Thank you.

Mrs. Lagomarsino.

STATEMENT OF NORMA LAGOMARSINO, WIFE OF CONGRESSMAN ROBERT LAGOMARSINO, CALIFORNIA; DR. SHERVERT H. FRAZIER, DIRECTOR, NATIONAL INSTITUTE OF MENTAL HEALTH, DEPARTMENT OF HEALTH AND HUMAN SERVICES, ROCKVILLE, MD; GINNY KRUMDIECK, SECOND VICE PRESIDENT, THE NATIONAL ALLIANCE FOR THE MENTALLY ILL, EUGENE, OR

Mrs. Lagomarsino. Good morning. Thank you for asking me to testify before your committee this morning.

I have to confess that I am appearing here this morning with very mixed emotions. I am happy to report that my son, who has suffered from mental illness for 17 years, is doing well today. But I cannot ignore the anguish he has endured and we his family have shared during the long years of his illness, and I must emphasize—

it is an illness. If I had realized that in earlier years, I believe we could have gotten help for my son much sooner.

Let me start by talking aboot how well my son is doing now. He is a student at a university, enjoying his studies and college life. He has a girlfriend and tells me he has never been happier.

Naturally, this takes the heavy burden of constant worry off our family. It reduces the tension among the family relationships and enables us all to lead more normal lives. It also allows me to talk about our experiences and personal feelings in a way that I never thought possible in a public forum.

I know families who confront the problem of mental illness sometimes wonder how they will have the strength to persevere. But perhaps, by knowing of the experiences of our family and son, those families will be encouraged to continue to give comfort and support to one who is suffering from mental illness.

As a mother, I make no attempt to hide my prejudices. My son was bright, well coordinated, handsome, good natured, and was always well liked. We will probably never know exactly what brought on the illness he suffered from for so many years. It may have been the combination of puberty and drug experimentation plus the influences of the late sixties on his very sensitive personality. It could have been genetics or a biological dysfunction of the brain, which recent research indicates. But whatever triggered his illness, it took 15 years to get him back to us.

In the beginning, we did not realize his cries for help. His anger and frustration were expressed in violence toward property, but never with the intention of hurting anyone, except perhaps himself. I used to ask myself what I had done wrong to cause him to act the way he did. Did I spoil him? Wasn't I strict enough? Should I have followed the advice of some who suggested we force my son out of the house to be left on his own to straighten himself out? It was not until later that I learned my son was suffering from schizophrenia, and that illness was very, very real.

We saw him through long years of trips to psychiatrists and expensive private hospitals; the panic of attempted suicide, and the heartbreaking reality of seeing him go to jail. It was only then, after he attempted suicide and was sent to a State hospital that we realized this incarceration was the only way he could be forced to get the help he needed. The State hospital began his program of medication and some therapy. After a year or so, it was decided his recovery program should be expanded to include occasional home visits and weekly sessions with a private psychiatrist. This program gave our son the hope and encouragement he needed to begin living in the real world once again.

Once our son left the State hospital, he went to a halfway house. From there, he went to a satellite apartment situation and now, to his own apartment. He is still obligated to attend programs at the halfway house and is still on probation, but he is only required to see his doctor once every 3 weeks. This system of checks and balances reinforces my son's progress, giving him the feeling of independence and self-sufficiency so important to his well-being, and giving us the confidence that his illness is being carefully monitored.

I have come to know that with constant medication, therapy, family love and support, my son's mental illness is treatable. The reality is that my son does not enjoy taking the medication; there are side effects. And it is not a cure. However, he knows that it is necessary and that it allows him to lead a more normal, productive life.

The experience with my son has led me to a number of conclusions and observations which I would like to share with you this morning.

First, we must strive to treat mental illness as just that, an illness that is treatable, just like diabetes and broken legs. All too often, the stigma of mental illness is so great that some seek to ignore it in the hope that it will go away. That is not the answer.

Second, one of the great frustrations in trying to help my son was the realization that we had no way to force him to receive the help we knew he needed. It took an antisocial act, a criminal act, on his part before he could be forced to accept medical attention for his mental illness.

Third, some mentally ill individuals receiving Federal assistance are not responsible enough to use those funds wisely. Perhaps the laws could be tightened so that a parent or guardian could administer those funds, thereby ensuring that the patient receives the help he needs.

Fourth, over 15 years ago, in an attempt to avoid having mentally ill patients permanently institutionalized, access to State facilities was reduced. The intention was to help these people in the community, but unfortunately, it has not worked. I believe that as a result, many of these mentally ill individuals have become homeless street people, or are being sent to jail for lack of a more appropriate alternative.

Fifth, organized support groups have been making significant contributions to increased understanding of mental illness and the role that community and family members must play. These support groups are making things happen.

In conclusion, the long, difficult fight to help my son lead a normal, productive life is the same challenge all families face when there is a family member suffering from mental illness. There are no easy solutions, and turning away from the problem or burying your head in the sand will not solve it. Laws must be changed which will permit help to be given to someone before a criminal act is committed, or someone is hurt. But most importantly of all, I cannot stress too strongly the significance of community involvement and the crucial role the family itself must play in supporting and encouraging a family member's battle against mental illness.

Thank you.

The CHAIRMAN. I am so proud of you. I want you to know I love you and Bob, and we really appreciate having you here. I think your testimony is really crucial to this hearing. I just want you to know that.

Senator KENNEDY. I want to second that, as well. I think one of the most difficult things is talking about the health problems in one's family. These are always things you would like to keep private, and it is extremely difficult. I think you have to recognize that from your kind of comments, given particularly the fact that those of us in the Congress both have access to professional help and assistance to get to the complexity in terms of the treatment for someone that you love, it really points up how challenging it is for people across the country. And I think that your circumstances, I am sure, are repeated by families all across the Nation. And obviously, we have no magic wands, but at least we can try and take your own experience and see what we can learn from it and see if we cannot help to give some paths to other families to deal with it.

We thank you very much for your testimony. It was very good.

The CHAIRMAN. We sure do. We are grateful to have you here.

Mrs. LAGOMARSINO. Thank you.

The CHAIRMAN. Dr. Frazier, let's turn to you now.

Dr. FRAZIER. Thank you, Mr. Chairman. It is a pleasure to be here, to have been invited.

I am Dr. Shervert Frazier, Director of the National Institute of Mental Health [NIMH], and I appreciate the opportunity to discuss our concerns regarding the barriers to care for persons with chronic mental illness.

As you all know, 1.7 to 2.4 million people in this country suffer severe, prolonged forms of mental illness. And about 125,000 to 130,000 of these persons are long-term residents of public hospitals. Some 770,000 reside in nursing homes. Of those in the community, a majority live with their families and in other settings such as group homes, sheltered apartments, and independent living quarters.

A sizable minority, however, cycle from institution to institution, from short-term hospitalization to temporary shelters to jails. Between 25 to 50 percent of the homeless in America are believed to be mentally ill.

We are particularly concerned with the increasing numbers of young adults who are suffering chronic mental problems. The concern with this highly mobile population is that they are unwilling to use the system as it now exists and seek care on a continuing basis. They have a tendency to be transient and move from place to place, and are heavily involved in substance abuse behavior. Because of this, they tend to get involved in the legal system and the correctional system in addition to the mental health system.

The chronic mentally ill persons have many needs—the same needs that every other human being has. Like the general population, they need housing, they need food, they need clothing, they need medical care, dental care, transportation, education, recreation, and they need money. They also need the personal support system consisting of persons who care for them as individuals.

Unlike others, they suffer from very profound and generally intractable disabilities, functional disabilities. They just do not carry over a function from one category of mental effort to another, from one learning capacity to another. Therefore, their capacity to work in regular employment is impaired. They have difficulties in the basic activities of daily living, and they experience the effects of ignorance and fear of mental illness on the part of others.

This population of the chronic mentally ill is a complex group, not easily defined. The condition reflects a combination of things, including a diagnosis such as schizophrenia, manic depressive psychosis, recurrent affective disorder, or organic brain syndrome; the level of social and psychological disability incurred as a result of the disease; and the duration of illness with chronic mental illness we are talking about the most serious kind of mental disorders.

In the Federal initiative, we have tried to accomplish some things relative to the critical role of States and localities in caring for persons with chronic mental illness. We have done a good deal to enhance the effectiveness of the service delivery system to the patients' needs.

Under the ADMS block grant, the dominant thrust in community mental health services has been toward expansion of the services targeted to chronic patients. These include partial hospitalization, case management, day care, and residential program services.

The Community Support Program strategies, which were encouraged by the Federal demonstration programs begun in the late seventies, have been adopted by a majority of the States as a primary model for caring for the chronic mentally ill, the psychiatrically disabled person. Over the past 7 years, each Federal dollar which has been expended through community support programs has generated on the State and local levels an additional $18——

The CHAIRMAN. Now, say that again. You are saying that for each Federal dollar we have been able to put into this, in bringing the State and local communities together and getting them to work on it, has brought eighteen additional dollars?

Dr. FRAZIER. Additional $18 in State and local resources have been targeted on this chronic mentally ill population.

The CHAIRMAN. I call that pretty good program.

Dr. FRAZIER. I consider it progress, but we need to work on it more.

We also realize and recognize that there are a lot of other entities outside the mental health field and outside the Federal Government which have to be involved in meeting the diverse needs of people with chronic mental illness. To that very end, the National Institute of Mental Health has actively sought collaboration with public sector, private sector, lay and professional groups, advocate groups, to address the various facets of this problem.

We have been fortunate, to have seen the emergence in recent years of a growing national network of mentally ill persons and their families who have brought to bear the interests of the community and the families. They are actively assisting by looking at the levels of governance, the attention being paid to treatment services, and the needs of the chronic mentally ill population.

There are some barriers which still remain. It is clear that barriers remain to the availability of and provision of comprehensive services. Economic considerations and, particularly, reimbursement biases against community-based care, are at the crux of the mental health systems ability to provide continuing and comprehensive care. One of the biggest issues we have, is the emphasis on the inpatient hospitalization of the mentally ill; 70 percent of the funds within the States go to inpatient services, while 70 percent of the episodes of illness are in the community. So we have this imbalance, this disparity, between State hospital inpatient funding and episodes of illness——

The CHAIRMAN. Do you agree with me that the community really is one of the best ways of helping people——

Dr. FRAZIER. Yes, it is. It is very much more enlightened, it is more progressive, and it is very much more helpful. And Mrs. Lagomarsino's testimony demonstrated how that has worked in her son's case.

The CHAIRMAN. Doctor, I do not want to cut you off, but your 5 minutes are up. But what I want to tell you is that I have read your statement, and it is a terrific statement, and I really appreciate you testifying here today.

Dr. FRAZIER. Thank you.

[The prepared statement and responses of Dr. Frazier follow:]

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Rockville MD 20857

Testimony of

Shervert H. Frazier, M.D.
Director
National Institute of Mental Health
Alcohol, Drug Abuse and Mental Health Administration
Public Health Service
Department of Health and Human Services

Before the

Committee on Labor and Human Resources
United States Senate

October 9, 1985

Mr. Chairman:

I am Dr. Shervert H. Frazier, Director of the National Institute of Mental Health (NIMH). I appreciate this opportunity to discuss our concerns regarding barriers to the care of persons with chronic mental illness.

The needs of people suffering severe and prolonged mental illness constitute a serious public health problem confronting this Nation. Over the past several decades, we have improved significantly our therapeutic and service systems capacities for responding to this population. During the same period, however, we have become increasingly aware of the intractability of certain obstacles to the provision of appropriate care.

In this statement I will: 1) describe the diverse population who comprise the "chronically mentally ill"; 2) describe NIMH activities targeted to this population; including, 3) our efforts to engage a variety of public and private sector entities in collaborative activities; 4) cite existing barriers to care; and, 5) comment on the critical role of research as the most promising means of fundamentally improving the quality of care and the quality of life experienced by severely mentally ill individuals.

Let me preface my remarks with a comment on terminology. In this statement, I will employ terms such as "persistent," "prolonged," and "long term," as well as "chronic," in describing the problem. In fact, there is increasing reluctance on the part of people in and outside of the mental health professional community to describe either mental disorders or mentally ill patients as "chronic"; unfortunate connotations of the term suggest inevitable deterioration and do not encourage sustained therapeutic intervention. Such pessimism is not warranted. Still, because "chronic" is widely used and understood, I will continue to use the word.

Chronically Mentally Ill Patients Today

A 1979 Department of Health and Human Services study estimated 1.7 to 2.4 million persons in this country suffer persistent, severe forms of mental illness. Approximately 900,000 of those chronically mentally ill people resided in institutional settings--130,000 in State mental hospitals and 770,000 in nursing homes. Between 800,000 (severely disabled) and 1.5 million (moderately to severely disabled) mentally ill individuals were estimated to be living in the community.

These are individuals with heterogeneous needs. Like the general population, mentally disabled adults need food, clothing, housing, medical and dental care, transportation, education, recreation, and money. Like every other person, they need a personal support system, consisting of persons who care for them as individuals. Unlike others, they suffer profound, generally intractable, functional disabilities. Their capacity to work in regular employment is impaired. They have difficulties with basic activities of daily living, and they experience the effects of ignorance and fear of mental illness and the mentally ill which remain widespread throughout this country.

Recent attempts to define this population have utilized a three-dimensional concept based on diagnosis, level of disability, and duration. Although they are useful for analytic purposes, we need to be aware that even these indices do not delimit precisely the population of individuals who suffer prolonged mental illness. "Chronicity" cannot be defined, for example, by diagnosis alone. While the psychotic disorders--schizophrenia and recurrent, major affective illness--typically characterize this population, other mental diagnoses such as organic brain syndrome and disabling personality disorder are not uncommon; also, alcohol and drug abuse disorders may complicate the course of mental disorders or may themselves become chronically disabling conditions.

"Disability" refers to the extent to which severe, prolonged disorder erodes an individual's capacity to function in many tasks of daily living. Disability may be evident in inadequacies in establishing interpersonal relationships, in meaningfully occupying one's own time, in coping with change or with stress, or in tending to personal health and hygiene needs. Objective measures of such limitations, however, are not in widespread use.

Prior to the era of deinstitutionalization, when severely ill patients were likely candidates for extended inpatient care, the duration of illness, as measured by total days of hospitalization during a given period or number of past hospitalizations, was used to define chronicity. With increasing numbers of individuals being treated in the community, however, and with the maturation in recent years of young adults who have reached an age of high risk for the onset of serious mental disorders, but who often are unwilling to seek care within established mental health service delivery systems, duration is an increasingly difficult measure.

Despite the difficulty of tracking a largely deinstitutionalized target population, precise data on the locations, circumstances, and needs of people with chronic mental illness are essential to the design of more effective systems of care. In a moment, I will describe ongoing efforts by NIMH to enhance the quality of data; what follows reflect preliminary analyses and anecdotal reports of trends that have occurred in the past few years.

Although the rapid rate of State hospital discharges evident in the 1970s has slowed, the trend continues. Today approximately 126,000 patients are long-term residents of these institutions. Of the chronically mentally ill in the community, we estimate that a majority live with their families, but we are aware that the proportion of severely ill patients who remain with or are discharged to their families is declining, a trend that has serious implications for their needs for personal support networks. An indeterminate but substantial number of others live in a variety of settings, including residential treatment centers, group homes, sheltered apartments, and independently. In addition, a sizeable minority cycle between hospitals, homelessness, and jails due to inadequacies in the State and local systems of services.

Definitive national data regarding the number of chronically mentally ill people in this country who are homeless does not exist. In 1984, the Department of Housing and Urban Development estimated that 250,000 to 350,000 people were homeless on an average night in the winter of 1983-1984. Other sources suggest that the cumulative annual count may range from two to three times the daily count to as many as two million persons. Recent estimates by the Department of Health and Human Services, the Department of Housing and Urban Development, and the American Psychiatric Association suggest that 25 to 50 percent of all homeless people may have some form of mental illness, or as many as 500,000 individuals.

Represented among the homeless who are mentally ill are an increasing number of the new category of young, chronically mentally ill adults to whom I referred a moment ago. Like others of their age, they are extremely mobile. Often distrustful of traditional care systems, they use them intermittently, if at all. Because they differ from traditional chronic mental patients in several significant ways--for example, increased use of alcohol and drugs, a higher incidence of suicide attempts and completions, and a greater tendency toward violence--many of these young chronic patients become enmeshed in the criminal system and spend periods of time in jail.

On any given day, an undetermined number of the chronically mentally ill can be found in the Nation's jails. The National Coalition for Jail Reform estimated the number to be more than one half million in the early 1980s; while this number is likely inflated as a result of the sampling and analytic procedures employed, it suggests the magnitude of the problem.

NIMH Activities in Response to the CMI

Over the past decade, a period marked by major shifts in Federal mental health policy and programs, the NIMH has strengthened its emphasis on chronic mental illness in service systems development and demonstration and in research.

ADMS Block Grant

In 1985, the mental health portion of the ADM Block Grant is $239.4 million, or almost 49 percent of the total grant. Except for the small percentage which may be used for administration, all the block grant funds are targeted for community-based mental health treatment and support services through community mental health centers.

The Block Grant has had a beneficial effect on services available to chronically mentally ill persons for two reasons: typically, the same State agency responsible for providing care to the chronically mentally ill in State hospitals administers the Block Grant and has a high degree of awareness of the needs of the population; also, the grant frees the State from the restrictions of prior categorical Federal funding and thus encourages programming these funds to State-determined needs.

The effect of the Block Grant on the operations of community mental health centers during the period 1981 to 1983 recently was documented in a survey of 71 centers in 15 States. The study sample was constructed carefully to represent differences in State support for community based services, geographic region. population, and organization of the State mental health authority. Methodologic tests showed that the sample adequately represented CMHCs nationwide and, thus, that generalizations made on the basis of this study are valid.

Overall, the investigators found that changes in service policies since 1981 have been aimed primarily at providing services for clients most in need, the chronically or severely mentally ill.

More than two-thirds of the centers reported changes in day treatment or partial hospitalization programs, 87 percent of these changes reflecting expansion necessary to accomodate an increase in the number and type of chronic patients being served.

In more than half of the centers, case management for chronic patients had increased. The study showed improved needs assessment, more interagency collaboration, greater cooperation among staff from different services, closer monitoring, more home visits and work with families, and better liaison with hospitals.

In addition, about half of the centers reported changes in residential programs, and, of those reporting changes, more than 69 percent indicated that programs had grown. This growth was evident in a variety of residential arrangements, including halfway houses, lodge programs, shared apartments, group homes, beds in private homes, and U.S. Housing and Urban Development projects.

Community Support Program

The Community Support Program (CSP) is a services demonstration program focused directly and exclusively on the needs of adult psychiatric patients who suffer severe and persistent disabilities but for whom long-term skilled or semiskilled nursing care is inappropriate.

Between 1978 and 1985, Federal CSP expenditures have totalled $46.6 million dollars and grants have been awarded to 50 States, two territories, and the District of Columbia. Further, for every dollar of CSP grant funding received, States have generated more than $18 in other resources to benefit chronically mentally ill persons. And, in approximately half of the States, new legislation has been passed to improve and expand services available to the target population. Wisconsin, for example, has mandated the provision of community support services; Missouri has passed a bill to provide a legislative base for developing and funding community services; and Ohio is in the process of altering its entire mental health system to a more community oriented basis.

Also, NIMH has sponsored seven national and 31 regional conferences to promote information sharing among mental health and human services personnel as well as patients and their families. And, in collaboration with the National Institute of Handicapped Research, the NIMH supports two Research and Training Centers, situated at Boston University and the Albert Einstein Medical Center, to conduct research on the rehabilitation of chronically mentally ill patients and to train staff from around the country in psychosocial rehabilitation treatment methods.

Homeless Mentally Ill

People who are homeless and mentally ill are among the most vulnerable and disenfranchised clients of the mental health and welfare systems. The functional characteristics common to chronic mental illness--an extreme vulnerability to stress, difficulty with the tasks of daily living, distrust of and difficulty in negotiating bureaucratic systems--tend to increase the susceptibility of mentally ill people to becoming homeless and, at the same time, make them less responsive to traditional strategies to acquire housing.

Over the past two years NIMH has awarded nine grants to States to assess the size, characteristics and services needs of the homeless mentally ill population and to demonstrate novel approaches to service delivery. I referred earlier to the inadequacy of data on homeless people who are mentally ill. An immediate research need is to define "homeless" in reference to deinstitutionalized and never-institutionalized chronically mentally ill people. Is the problem simply a matter of shelter and basic support needs? Or should the definition include an assessment of the quality of social supports and relationships? We need to attend carefully to the definition of "mental illness" in the context of homelessness. Too restrictive a definition will understate the problem; too loose a definition runs the risk of trivializing it.

Collaborative Activities

Throughout this discussion, I have referred repeatedly to the diversity of needs experienced by chronically mentally ill patients. Clearly, the requirements of this population extend well beyond the capacities of the NIMH or the mental health field to respond.

An encouraging development evident in recent years--and one that contrasts sharply with practices in the early years of deinstitutionalization--has been the increasing number of innovative and productive collaborations between and among NIMH, other Federal agencies, and many components of the mental health, health, and human services fields. I mentioned earlier our joint support with the National Institute of Handicapped Research of two Rehabilitation Research and Training Centers in Mental Health. Other collaborative relationships include:

- Work with the Social Security Administration to update standards for use in determining disability due to mental impairments; the standards were updated early this year to reflect changed diagnostic practices in psychiatry, the chronic nature of some mental disorders, and new knowledge about the phenomenology of these disorders.

- A new interagency agreement between NIMH and the Rehabilitation Services Administration to support jointly two training programs for mental health and vocational rehabilitation professionals in the use of vocational rehabilitation training techniques with chronically mentally ill individuals.

- A program developed in response to a request made by the U.S. Conference of Mayors in which NIMH will provide technical assistance in identifying the mental health needs of homeless people in eight cities; additional support for this project is being provided by the Office of the Secretary, Department of Health and Human Services.

- A national conference, sponsored by NIMH and convened by the American Public Health Association, that brought representatives of 14 major mental health organizations together to discuss public policy regarding the homeless mentally ill.

- A joint effort between the NIMH and the National Restaurant Association to create employment opportunities in the food industries for persons disabled by chronic mental illness.

Barriers to Care

Despite the many accomplishments I have described, there persist substantial barriers to the availability and provision of comprehensive, appropriate services to all chronically mentally ill individuals who require them. Over the past decade, widespread fiscal constraints have tended to overshadow gains that have been realized in the clinical status and quality of life of thousands of chronically mentally ill patients. The results of deinstitutionalization are being "demythologized," revealing underlying processes of reinstitutionalization and transinstitutionalization and a deterioration of the quality of care available to many patients.

Economic considerations and, particularly, reimbursement biases against community-based care, are at the crux of the mental health system's compromised ability to provide continuing and comprehensive care to chronically ill patients in the community. We must develop an equitable system of financing mental health care that encourages flexibility and the provision of appropriate services in appropriate settings.

Apart from specific questions of reimbursement, it is evident that a massive shift from a hospital-based to a community-based system of care necessitates a period of dual systems funding. At the present time, approximately 70 percent of State mental health budgets are devoted to State hospitals. Seventy percent of all episodes of mental health care, however, occur in community settings. Until we achieve needed modifications in the financing system to permit high-quality community care, we must maintain the quality of care in State mental hospitals.

In the era of post-deinstitutionalization, an immense and complex mix of systems is involved in meeting the needs of chronically mentally ill individuals. Constant vigilance is required to ensure that modification in one component of a system is acceptable to another, or, if not, to make the adjustments needed to eliminate the new problem or to seek alternative strategies.

While barriers to care resulting from imbalances within service systems are challenging, equally crucial obstacles are encountered in attitudes regarding chronic mental illness that are held by the public at large, as well as by many professionals in the mental health field. We are fortunate that we have seen the emergence in recent years of a rapidly growing national network of mentally ill individuals, their families and other citizen advocates who are encouraging, supporting, and demanding that an appropriate level of attention be paid, at all levels of governance, to the needs of the chronically mentally ill.

The Role of Research

The primary programmatic responsibility of NIMH is the conduct and support of research directed to the understanding, treatment, and prevention of mental illness and the promotion of mental health. And it is through our commitment to this responsibility that I believe we ultimately will address the needs of people suffering chronic mental illness.

Research needs in the area of chronic mental illness are both general and specific; that is, basic studies of brain and behavior, of the epidemiology of mental disorders, and of cross-cutting clinical methods, which will contribute to an improved understanding of all forms of chronic disorders must be complemented by programs and projects which target discrete disorders.

In Fiscal Year 1985, NIMH allocated $63 million for basic studies of brain and behavior. The basic research portfolio encompasses investigations designed to elucidate brain functions that may be implicated in mental illness; studies that provide fundamental information on how mental and emotional capacities develop and function throughout the lifespan in mental illness and in health; and research which links brain function to behavior.

Traditional concepts of the brain are based on the position and arrangements of cells in tissue. More recently, however, research on the chemical distribution of neuromodulators and their circuitry in various brain regions are yielding a more sophisticated concept of the brain as a structure comprised of chemically identifiable groups of neurons that project into various parts of the brain. This new perspective has led to the identification of subregions of the brain that are chemically unique and, in turn, to reconsideration of the functional significance of some brain structures.

These approaches are well-illustrated in the work of Joseph Coyle of The Johns Hopkins University, in Baltimore, Maryland. In studies of the development and plasticity of the neocortex in rat brains, Coyle found that lesions in the basal nucleus of the brain caused reduced amounts of acetylcholine, a neurotransmitter, to reach certain cortical areas. Because the disruptions of acetylcholine neurotransmission resembled those reported in humans with Alzheimer's disease, Coyle examined the brains of patients who had died of the disease; he found severe and selective degeneration of acetylcholine-using neurons in the basal forebrain. The finding provided the first example of a transmitter-specific neuronal lesion that may account for a major, chronic disorder of cognitive function. The work that led to the finding demonstrates clearly how basic studies aimed at understanding fundamental brain function in the rat resulted in a neuroanatomical discovery of fundamental importance to clinical psychiatry.

As these efforts are underway, the NIMH is sharpening its focus on the immediate research needs of specific disorders. Toward this end, the Institute, with consultation from the field, has restructured its major clinical research support program so as to focus programs on the discrete needs of major diagnostic categories and special populations.

I referred earlier to the three diagnostic categories that most typically account for chronic mental illness: schizophrenia, affective disorders, and organic brain syndrome, particularly, senile dementia of the Alzheimer's type. As recently as two decades ago, a diagnosis of schizophrenia or senile dementia nearly inevitably implied need for longterm institutionalization. For the majority of patients, course of illness would be marked by progressive deterioration in core clinical symptoms, compounded by crippling diminishment of psychosocial coping capacities; the prognosis for patients experiencing these accumulated deficits was bleak. In sharp contrast, major affective disorder tended not be be perceived as a chronic mental illness. Rather, depression was viewed either as an isolated, situational response to excessive psychological or environmental stress or as a manifestation of characterologic weakness.

Recent research has influenced these perceptions profoundly. Refinements in pharmacotherapy, the development of psychosocial management techniques, and the proliferation of community-based mental health services have dispelled much of the therapeutic nihilism formerly associated with schizophrenia, and have permitted many patients with this diagnosis to retain and even regain functional capacities that formerly would have been lost. With respect to the dementias, advances in diagnostic practice have enhanced substantially clinicians' capacities to recognize true dementia with a high degree of sensitivity and to differentiate and treat disorders such as depression, which might confound or camouflage the brain syndrome; additionally, progress in elucidating the biochemical substrates of senile dementia has suggested strategies for modifying the core symptoms of Alzheimer's disease pharmacologically. Perhaps the most striking accomplishments are seen emanating from research on affective disorders: these today are acknowledged to be serious chronic disorders with a strong genetic component. Of greater significance, they are recognized also to be highly amenable to a wide range of therapies, including interventions designed to prevent recurrences of acute episodes of the illness.

In Fiscal Year 1985, NIMH allocated $18.4 million for funding projects on the schizophrenic disorders. Examples of ongoing projects include an investigation by Marion DeMyer, at Indiana University, in which the investigator is using Magnetic Resonance Imaging to study the brains of schizophrenic patients and normal controls. She is further subdividing the schizophrenic patients into those with and without obvious neurological pathology. The study will also compare these images to computerized tomography scans. The goal of the work is to improve the characterization of both physiological and structural brain abnormalities in schizophrenia.

At The Johns Hopkins University, Michael Kuhar is studying the localization of antipychotic drugs in normal and schizophrenic subjects. By using positron emission tomographic imaging techniques, he is able to determien areas of the brain where the drug accumulates and to quantify the amount of drug bound to dopamine receptors. This work holds the promise of leading toward development of more specifically acting antipsychotic drugs. Further, characterizing changes in dopamine receptor numbers in schizophrenia may be important in understanding the complex etiology of the illness.

Also, NIMH investigators, in collaboration with research teams at five sites, have begun a major study of treatment strategies in schizophrenia, to assess the value of both drug and psychosocial therapies. The study is an attempt to find reduced dosage strategies that that may decrease the risk of tardive dyskinesia. Because reduction of dosag increases the risk of relapse, the study will test the usefulness of a psychosocial management strategy, both to offset the increased risk of the relapse and to enhance social functioning.

A variety of efforts are underway to identify clinical and/or biological markers that could meaningfully and consistently separate schizophrenic patients from those with other psychoses. An ability to subtype schizophrenia might facilitate prediction of the course of the disease, treatment response, familial risk, and so forth. A research initiative on this topic--often called heterogeneity of schizophrenia--is now being developed by NIMH staff.

While efforts of comparable scope and complexity are being supported in other areas of chronic mental disorder, the current state of knowledge about a given disorder or problem may dictate different emphases. With respect to the affective disorders, for example, an array of treatment strategies of proven effectiveness and safety currently exist; more immediate needs are for research on the etiology of the disorders, better understanding of the dynamics of suicide, more effective means of preventing recurrence of episodes, and improved understanding of the ways in which these disorders are recognized and treated by general health care personnel and mental health specialists. Last year, NIMH, in collaboration with the Office of Medical Applications of Research, NIH, sponsored a Consensus Development Conference on the "Pharmacologic Prevention of Recurrences of Mood Disorders," and disseminated the proceedings of this conference to the field.

In contrast to the affective disorders, Alzheimer's disease will benefit substantially from an expanded, fundamental understanding of basic brain processes. While this work continues, clinical emphases currently are directed toward improved management of the illness, and particularly, research designed to enhance the helping and coping capacities of family members.

Efforts to refine mechanisms and programs of service delivery to chronically mentally ill individuals have shown repeatedly in recent years that, for some patients, the availability of adequate community support resources does not in itself ensure that appropriate treatment will--or even can--be provided. The disease interferes. This is a clinical reality and service needs will continue to mount, as will the human costs of mental illness, until our research efforts allow us to prevent and better treat and rehabilitate those persons with severe mental illness. At the same time, however, epidemiological research and studies of the overall mental health service delivery system represent urgent and essential elements of efforts targeted to the chronically mentally ill. Toward those needs, NIMH allocated more than $13 million in Fiscal Year 1985 for epidemiological and service systems research.

Conclusion

For this Nation to respond to the needs of its citizens who suffer chronic mental illness will require the participation of many sectors of society and the collaboration of numerous components of Federal, State, and local government. In this national effort, the primary and essential role of the National Institute of Mental Health is the conduct and support of research. We intend to utilize our resources wisely, to continue to emphasize areas of research where the need is greatest, and to ensure that as new information is obtained, it is communicated to health and mental health care providers, policymakers, and families of the chronically mentally ill.

Thank you.

RESPONSES BY DR. FRAZIER TO QUESTIONS SUBMITTED BY SENATOR KENNEDY

1. **Dr. Frazier, you have heard the eloquent testimony of the other members of the panel here today. Would you agree that in far too many places in the country there is no effective system of community care in place? And don't the chronically mentally ill and our society pay a heavy price for that omission in terms of unnecessary pain and suffering and waste of our human resources?**

I would agree that there are areas where there are ineffective systems of care for people who suffer from chronic mental illness. Many States have made this population a number one priority and have promoted the development of local community support programs, including psychosocial rehabilitation, emergency care, and case management. A difficult task that needs continued emphasis by NIMH, working with States and communities, is the development of entities at the local level who will take leadership responsibility for coordinating comprehensive systems of care for this population.

These entities would assure that persons with long-term mental illness would not "fall through the cracks" and end up unnecessarily rehospitalized, placed in the criminal justice system for a minor infraction, or become homeless.

2. Is the problem primarily lack of resources or failure to use existing resources effectively, particularly in terms of putting too much into institutional care and not enough into a truly comprehensive system of community care?

Answer: There is a need for more resources and a need to better utilize existing resources. A study conducted by the National Association for State Mental Health Program Directors for NIMH shows that in 1983 about 70% of all State funds for public mental health care goes to institutions rather than to community programs. This is despite the fact that over 70% of all patient care episodes take place in the community. Most States need better state-wide systems planning in order to generate new resources and better allocate existing resources.

3. The last reauthorization of the ADAMHA block grant increased funding for the Community Support Program and established a new system of State planning grants. Would you say those were important first steps in dealing with this problem?

Answer: The 1984 amendments established a $20 million authorization for service demonstrations related to the chronically mentally ill, seriously emotionally disturbed children, and the elderly. $10.5 million was appropriated in FY 1985 under this authority; this is about the same level as appropriated under the research authority in FY 1984. The new State Comprehensive Mental Health Planning Grants provide States with additional resources to help them plan for the coordinated use of various sources of funds--Medicaid, Medicare, vocational rehabilitation, housing, social services--along with State funds and private third-party funds--to better meet the needs of the mentally ill. Improvements in State planning across the various human service programs that should be serving the long-term mentally ill is an important first step.

4. The National Plan for the Chronically Mentally Ill estimated that in 1983 approximately 45 percent of total expenditures on this population--$3.9 out of $8.7 billion--was provided by the Federal government. Is this a good ballpark estimate of the relative weight of State and Federal funding? Doesn't this suggest an important Federal responsibility to see that we use those funds wisely through an effective community service system?

Answer: Our staff recently estimated that of the $10.6 billion estimated total expenditures on services for the chronically mentally ill in FY 1983 approximately $4.9 billion or 45% of the total was provided by the Federal government. Therefore, your figure is a good ballpark estimate of the relative weight of Federal funding versus other funding. I believe that this Federal investment does suggest an important Federal responsibility to see that funds are used wisely through effective community service systems. NIMH has been carrying out its responsibility in this area through a variety of programs including service systems research, service demonstrations, State Comprehensive Mental Health Planning grants, and a variety of technical assistance and consultation activities for State and community agencies.

5. Evaluations of the Community Support Program have shown that hospitalization rates can be reduced by as much as 50 percent. Do you think that would be a reasonable projection of the national experience if we had good community care systems in place everywhere?

A national CSP evaluation project studied 4,288 clients in 15 local CSS programs. Although this was shown to be a highly disabled group with a median yearly income of only $3,900, the study demonstrated a 50 percent reduction in hospital use and concluded that the individuals were living at moderately good levels of adjustment in the community.

In addition, other studies demonstrate the effectiveness of appropriate community-based services.

A study in Minnesota reported a 30 percent decrease in hospital days used when an area with a CSS was compared to an area without one.

A local program in Florida reported a 90 percent reduction in the number of hospital days used over a 2-year period subsequent to implementing comprehensive CSS services. The State of Florida, in a 1983 evaluation study, showed a 40.2 percent decrease in hospitalization in control counties with CSSs as compared to 6.1 percent in counties without CSS programs.

An analysis of the Training in Community Living (TLC) program in Madison, Wisconsin, compared individuals involved in the TLC program with those remaining in the hospital. Not only was hospitalization virtually eliminated for the people in the TLC, but these people exhibited significantly less symptomatology, scored higher on measures of satisfaction with life, spent less time unemployed, and had more positive social relationships.

Based on data from these and other research and evaluation studies, it is clear that involvement in community support programs and systems significantly reduces rehospitalization and results in improvements in the ability of long-term mentally ill clients to function.

6. Q. In a recent speech on the homeless, you noted a shortage of appropriately trained and motivated professionals. It would seem that there is an urgent need to identify, document and disseminate successful program models for the chronically mentally ill, including the homeless. What contribution could NIMH make to these problems? What changes do you need to make the maximum contribution?

A.

o NIMH will continue to work with State mental health authorities to identify and disseminate information about existing model programs and promising approaches within their States to provide care, treatment, and rehabilitation for the chronically mentally ill living in the community.

o Additionally, through its national Learning Community Conferences, information on model programs has also been shared between States.

o However, it has become apparent that certain segments of the chronically mentally ill population are still not adequately served---specifically, the homeless mentally ill, seriously disturbed children and adolescents, and the elderly. More work is needed to develop innovative demonstrations that specifically address the needs of these special populations in local communities.

o NIMH has awarded a contract to the U.S. Conference of Mayors to provide technical assistance to eight cities which are significantly impacted by the problem of large numbers of persons who are homeless and seriously mentally ill. Regional meetings will be held in five different areas of the country to exchange information between these cities and others on successful approaches to serving this vulnerable and disabled population.

7. Q. Do you agree that aggressive outreach programs by Federal agencies--particularly SSA--and state and local mental health authorities could make a major contribution to improving care for the homeless chronically mentally ill, one of the most tragic of these populations?

A.

o Outreach programs are essential for assisting many chronically mentally ill persons who would not ordinarily seek out help on their own. Among the homeless, the mentally disabled are probably least able to know where to find agencies, programs, and resources and most vulnerable to the pressures created by too many questions, too many forms, and long waits. Because of this, chronically mentally ill persons may never reach the doors of shelter, food, and service programs.

o Over the past year, the Social Security Administration has issued a guidance to its 1300 local field offices, encouraging greater outreach to the homeless. Under these procedures, SSA responds to requests to take claims and conduct interviews at facilities that provide services to the homeless---shelters, churches, and so forth. Preliminary feedback indicates the usefulness of this approach.

o However, outreach must extend beyond Federal agencies alone. Most importantly, local housing and human service providers need to find effective ways to reach out and serve the homeless mentally ill. Several innovative outreach/case management models in New York (e.g. Project Reachout, Project Help, and the Midtown Outreach Project) are excellent examples of this approach.

8\. Both Medicare and Medicaid currently have a bias toward inpatient care. Would you agree that coverage of community-based services by these programs could have a major positive impact on this population and would be a more effective use of scarce resources?

Medicare and Medicaid are health insurance programs that are biased toward inpatient care because (1) inpatient care is primarily medical in nature and (2) most "treatment" for long-term mental illness has traditionally occurred in a hospital. During the last decade, we have seen a major change in the locus of care for people with long-term mental illness from the hospital to the community. This care consists of treatment, primarily with psychotropic medications, and psychosocial rehabilitation. A positive impact on this population might be gained by increased coverage for both community treatment, with an emphasis on case management, and psychosocial rehabilitation from one funding source.

This would also provide treatment of persons in the community and prevent unnecessary hospitalization.

The CHAIRMAN. Mrs. Krumdieck, let's turn to you at this time and finish with your statement. This has been a great panel so far.

Mrs. KRUMDIECK. Good morning. I am Ginny Krumdieck, and I am from Eugene, OR. My husband and I have five children, one of whom, Steve, is afflicted with schizophrenia. He was diagnosed 12 years ago with this very, very severe illness.

It is such a thrill for me to be here, believe me. Twelve years ago when our son was diagnosed and for the first couple of years following that time, I felt as though I was not going to survive. And then, to find myself with the opportunity to come to Washington and to be able to share with Senator Hatch and others the problems that we as families and the mentally ill have gives the kind of hope that I cannot even begin to tell you.

When other families with whom I am aligned in a family support group in Eugene found that I had been invited to come here, you could not believe the excitement that they all felt. I want you to really know that because, again, it gives that feeling of hope that a lot of the time you simply do not have.

Another great thing that gives one hope is the National Alliance for the Mentally Ill. Five years ago, in Madison, WI. we had the organizational meeting for this organization, and in 5 short years we now have 30,000 families across the country affiliated with the National Alliance for the Mentally Ill. We have 500 affiliates in all 50 States. None of us need find ourselves isolated and alone as each one of us was in our own individual ways, in our own individual corners of this country, when our sons and daughters and other members of our families were diagnosed with schizophrenia or the other serious mental illnesses.

I am hoping so much that all of you will have an opportunity to read the written testimony that I sent in. Also included along with that is a brochure—and I brought a few with me today, if anyone is interested in having one. It is called Mental Illness is Everybody's Business. I attached that with my statement, because it again speaks specifically to what schizophrenia is, what manic depression is, depression, et cetera.

One of the subjects in my written testimony has to do with the fact that families are "coming out of the closet" all over this country. I know "coming out of the closet" can be kind of a trite phrase, but it seems to fit. Back when our son was diagnosed with schizophrenia, I went to our local mental health clinic in our county, and I asked for help in starting a family support group. My request went through all the channels, ended up on the director's desk, and his answer back to me was, "Well, maybe, but we are going to have to open a case on all of you families."

In other words, families were—and regrettably, still are, in many quarters—looked at as the causative factor. And you might imagine what this does for a family; to have a son or daughter diagnosed with a mental illness, and on top of that, have somebody tell you either blatantly or subtly that somehow or another you are the cause is enough to kill you.

So again, I want to thank you so much for allowing me to come and share with you.

The gentleman whom I talked with over the phone and thereby received an invitation to come, asked I tell you about the apartment complex we have in Eugene, so I will just take a couple of minutes to do that.

In our community, housing, as it is all across the country, is a No. 1 priority, but it just sat there as the No. 1 priority for 5 or 6 years in the overall plan that our county had for services to the mentally ill—and nothing was happening. Each year, it just came up on top of the list.

In 1979, after we families had become organized in our community and I was serving as chairperson, I, along with some of the other members of our group, convened what we called a housing dream workshop. We got families and mental health professionals together, and we met all one Sunday, from early morning until late afternoon. I recommend it to anyone who is trying to solve the housing problem. The first thing we told each other that morning was to throw out all of the negative "can't dos." We had heard that all the time.

By the end of that day, we had the design for the apartments that we now have, and we had developed a philosophy of services. We have a 35 one-bedroom apartment complex in Eugene which serves adult mentally ill. It was put together with an extremely unique, cooperative effort, using public and private funds.

My husband is a builder-developer, so some private funds came from there. In Oregon, we have what is called the Oregon State Housing Division, which works something like a bank. It provides mortgage moneys for residential facilities for the elderly, low-income families, and for the handicapped.

Prior to us accessing funds from the Oregon State Housing Division in Oregon, they had never disbursed any funds for the mentally ill. Believe me, we had to do an awful lot of education for them to even look at our population as one for whom they would provide moneys to build the place we have.

The other part of the cooperative effort was the State Mental Health Division. It provides the funds to pay the staff who work there giving the kind of support that our people need. And then we have one really key component that is no longer available, and is one of the reasons why I spoke throughout my written testimony about how I believe that the Federal Government also needs to be involved along with communities and States. The key component we have is section 8 rental subsidy for our apartment complex, which means that people can live there, receive support services and pay no more than 30 percent of what they have coming in. That was another important ingredient in being able to put this together.

The CHAIRMAN. Well, thank you. I think you have been very, very helpful.

[The prepared statement of Mrs. Krumdieck and response to questions submitted by Senators Hatch and Kennedy follow:]

The National Alliance for the Mentally Ill
1901 North Fort Myer Drive • Suite 500 • Arlington, Virginia 22209 • (703) 524-7600

October 9, 1985

Dear Members of the Senate Labor and Human Resources Committee:

Dedication I dedicate this testimony to the indomitable spirit of families of the severely mentally ill, many of whom I'm fortunate to know, all across this country. I am proud to be a member of the large "family" of families everywhere who have decided not to let mental illness destroy their lives and spirits and are out there every day doing something to improve the lives of those who suffer from mental illness.

Personal Introduction I am Ginny Krumdieck and I live in Eugene, Oregon. My husband and I have five grown children, one of whom, Steve, is afflicted with schizophrenia. Steve, age 32, was diagnosed with this most serious mental illness twelve years ago. At that time, our whole family life was turned upside down. The only way for me to survive when tragedy strikes is to do something to make as much good happen out of it as possible. This, I have found, is also a driving force for the families I have met throughout our nation. Individually and collectively heroic efforts are being made in a climate of often overwhelming odds.

Since I have been the family member invited to give testimony, I will further introduce myself to you by way of sharing some of the activities I have been involved in. But please know that a whole array of actions is taking place in all corners of our country, and that I am just one of many family members dedicated to improving the lives both of the mentally ill and their families.

Twelve years ago when our son was diagnosed, there were no avenues for support or education for families of the mentally ill in our community. Families were looked at as the causative factor of the illness -- a travesty still all too often perpetrated on families -- and a very painful message given to me when I went to our local mental health clinic for assistance in organizing a family group. As desperate as our family's needs were, I somehow had the wherewithal to turn down the "Well, maybe, but we'll have to open a case on each family." Clearly, we had to rely on our own resources. Finally, in 1978 our family group in Eugene was founded by myself and another mother. It has grown to include over a hundred families.

I was hired for a nine-month period in 1981 to provide technical assistance in the formation of family groups. In this capacity I also wrote A Grower's Guide: How to Start a Family Support Group. The Oregon Advocacy Project was the forerunner of our state organization, Oregon Alliance for the Mentally Ill, an affiliate of the National Alliance for the Mentally Ill.

As with many families, I serve on a number of mental health county and state agency boards. As a member of the Oregon State Mental Health Advisory Council, I chaired for a year the implementation process based on a state legislative bill calling for enhanced physical testing. In 1979, as chair of our family group, I convened a housing "dream" workshop came the basis for the building design and the philosophy for the support services of the Hawthorn Apartments, a thirty-five unit complex in Eugene which houses chronically mentally ill adults. Through a unique cooperative effort using private and public monies, which took three years to put together, we have what is considered to be a model residential program.

Several other members of our locally family group and I are currently serving with other League members on a League of Women Voters of Lane County research team studying the Lane County adult mental health system. In part as an outgrowth of the interest generated by this local study, the League of Women Voters of Oregon selected this subject as a state study-item last May.

In Madison, Wisconsin in September, 1979, my husband and I were one of 250 families to gather together to form the National Alliance for the Mentally Ill. Grassroots groups had been sprouting up here and there, mostly unknown to one another. Now numbering over 30,000 families, NAMI based in Arlington, Virginia, has 500 affiliates in fifty states I am presently serving my last year of a three-year term as a NAMI board member. We are developing a housing task force for which I will serve as chair.

In none of these activities have I been involved alone. I am part of a team. Several times I have been dubbed "a cheerleader," and that feels okay to me. We need you on our team. In a lot of ways we've gone as far as we can or could be expected to go.

Why Join Our Team?

- One in 20 American families lives with major mental illness. Mental illness can strike anyone at any time, even a senator or his or her family.
- Mental illness costs our country an estimated $67 billion each year.
- On a more personal level, let me share a couple of findings about the parents of mentally ill persons from a study done by a family group in California:

  One half of the parents are 60 years or older.
  The majority have attended college.
  Over half are or were in professional, managerial or technical occupations.

I include this information for three reasons:

(1) Mental illness is no respector of a person's place in life.

(2) There is a lot of team expertise among family members for you to draw upon.

(3) Do something NOW before we are dead.

<u>What crushes the minds and hearts of families</u>:

We see ourselves each year getting older, less able to cope. No matter how hard we work turning over stones, it's not enough. Under the stones we encounter boulders. I have this haunting picture in my mind's eye of us families in graveyards all over the country with our hands sticking out still trying to take care of our ill family members, who continue to wander through the maze of a mental health system no more responsive to their needs as human beings than it is today.

We see a mental health system so underfunded and attitudinally charged that families are assigned the role of primary care givers. Several studies indicate that 60 percent of mentally ill adults are discharged from hospitals back to their family home.

We see all forms of the media characterizing our ill family members as violent killers, when we know that the mentally ill are statistically no more violent than anyone else. We know our people all too often become the victims of aggression, not the aggressors.

We see our ill relative not deinstitutionalized but TRANSinstitutionalized. Families in increasing numbers are finding themselves visiting their ill family member through the bars of a jail or a prison.

We see our family members denied rights in the areas of housing, employment, and insurance. Many parents have endangered their old-age security by depleting family funds in an effort to find a cure for their ill family members.

We see and feel the strain placed on family relationships. A number of siblings leave home to be heard from maybe at Christmas time. Mothers are often the ones to carry the heaviest load, with their emotions pulled in all directions.

We see our dual-diagnosed people shunted from one mental health program to another because "they don't fit." We know many of the young adult chronic population are also substance abusers; the system for the most part does not seem to recognize this. Systems may be compartmentalized, but people's needs are not always. If the need doesn't fit the compartment, the PERSON may go untreated.

We see deinstitutionalization as a humane premise with some inhumane results. The majority of the mental health dollars are still tied to state hospitals with a pittance for community services.

We see some of our people recovering sufficiently to tackle a few hours of work and the powers that be deem them to be "gainfully employed" and cut off their entitlements. And away goes their medical card. The stress of having this happen triggers another psychotic episode -- and we start all over again.

We see the tragic effects of tardive dyskinesia, a possible side effect of all antipsychotic medications. The disorder causes involuntary muscle movements which can be so mild they go unnoticed or so severe a person is nearly disabled. The latest American Psychiatric Association's Task Force on Tardive Dyskinesia reports an estimated 10 percent to 20 percent of those taking neuroleptic (anti-psychotic) medications develop some symptoms of tardive dyskinesia. Other studies report higher figures. Percentages lose their meaning when it strikes your family. I know; our son, Steve, has this added affliction.

We see that research on psychiatric diseases is more dependent on the federal government than is research on other disease, as few foundations or philanthropists have given funds for this. It's enough to make you sit down and cry if what one outspoken critic of the National Institute of Mental Health says is even anywhere near true: The amount spent on schizophrenia research is approximately the same amount the federal government spends on tooth decay!

Why are families pouring out of the closet?

First, within the past decade or two, science has demonstrated convincingly that the most serious mental illnesses are caused by diseases of the brain. The cause, in some cases, seems to be linked to hereditary predisposition, but in many cases, it simply is unknown. In this respect, it is similar to heart disease, epilepsy and cancer. It is no longer shameful to acknowledge that you have a mentally ill loved one that science now tells us suffers from a disease. It is easier to come out of the closet.

The second reason people come forward is because there is a place to go -- a family support group. There you give and get emotional support, an opportunity to tell your story to other families who understand every word you say. You exchange valuable information. Then you can move on to become an advocate for better services for mentally ill persons, for more research, and help to educate the public about mental illness.

What are NAMI's major legislative and public policy goals?

1. Support substantial increases of the NIMH research and research training programs in keeping with NAMI's goal of a national war on mental illness and the 1984 recommendations of the National Academy of Science's Institute of Medicine.

* Support an appropriation for FY 1986 of $260 million for research and $24 million for research training.

2. Promote the development and improvement of complete systems of mental health care for chronically mentally ill persons.

* Promote and support the implementation of new state mental health planning initiatives in several states, with the involvement of AMI members on state planning councils. Support full $5 million appropriation for FY 1986 for planning grants to states.

* Encourage psychosocial rehabilitation services as a core service of community mental health treatment, as authorized by 1984 amendments to the Alcohol, Drug Abuse and Mental Health Block Grant law.

* Support continued expansion of the NIMH Community Support Program, including CSP demonstration projects, to a level of $20 million for FY 1986.

* Urge federal initiatives and incentives to fund community mental health care for homeless mentally ill persons.

* Support greater not less effort by the federal government in providing housing for mentally ill persons through existing programs such as Section 8 rent subsidy and Section

202 long-term loans, as well as tax incentives to encourage community-based housing.

3. Improve access to all services required by mentally ill persons in communities such as Medicaid, income programs (SSI/SSDI), vocational rehabilitation, and social services.

* Enact legislation to permit and help mentally ill persons receiving federal disability benefits to become employed by removing work disincentives in current law and authorize rehabilitation services to foster independent living.
* Amend at the federal level the Medicaid law to clearly authorize psychosocial rehabilitation services as an eligible service; state Medicaid plans should include as an optional service appropriate rehabilitation-focused community based services for chronically mentally ill persons.
* Open up the federally-funded vocational rehabilitation system for improved access and appropriate training for mentally ill persons.
* Urge federal initiatives to improve access to disability benefits for homeless mentally ill persons and others at risk of becoming homeless.
* Enact federal fair housing legislation that includes mentally ill persons as part of coverage of handicapped persons as a protected class under the Fair Housing Act and

to override restrictive local zoning ordinances which prevent establishment of group homes for mentally ill persons.

Closing Observations

Some states are more open to family input than others. A lot depends on how well the families are organized and who happens to be in political power at the time. This makes for a very iffy situation indeed. The same situation exists right down to the local communities. If we are ever to solve problems faced by the mentally ill and their families, then I believe it is going to take the federal government making a bi-partisan, consistent stand and sticking to it. We cannot expect states and local government to solve the problems without a clear message from Washington. Many local problems are tied to federal legislation. Divestiture by the federal government from the plight of the mentally ill and their families is unconscionable. The federal government must lead the way by waging war on mental illness.

Finally, I have just learned that Senator Kennedy has introduced legislation that seeks to influence some of the public policy goals I set out above, particularly affecting housing, medicaid, and state planning for a restructured mental health system. I commend him for these initiatives and other members of Congress who will cosponsor these bills.

Questions for Mrs. Ginny Krumdieck.

Submitted by Senator Hatch, in regards to hearing on "Barriers to Health Care", October 9, 1985.

1. You discuss helping the chronically mentally ill through cooperative public and private sector support. In your discussions with other family support groups, has this been their same experience? What more can we do to help in these types of efforts?

Answer: It is important that the Federal government not abdicate all leadership in the mental health/mental illness national arena. The federal agenda for the mentally ill is an important one: MINH's research and community support programs, SSI and SSDI, Medicare and Medicaid, vocational rehabilitation, and housing.

Only so much can be accomplished by our own bootstraps efforts. We need federal leadership in devising a fair system of care for the mentally ill. The Health and Human Resources Committee ban became a Congressional focal point for leadership, legislative ideas, a clearing house for information, and a place one can be sure there will be sympathetic understanding of the needs and circumstances of mentally ill citizens in America.

The systems decisions for mental health care are made at the state level. The federal incentive to move states to action, correct action, is a lever not to be relinquished -- whether through the ADM block grant, or other programs through which federal dollars flow.

It is a shame the Mental Health Systems Act -- the product of years of thought and advocacy -- was never tried. The Committee can keep alive its purposes and objectives.

Submitted by Senator Kennedy, in regards to hearing on "Barriers to Health Care", October 9, 1985.

1. Mrs. Krumdieck, you comment in your testimony that "divestiture by the Federal government from the plight of the mentally ill and their families is unconscionable." Would you care to elaborate on that statement.

Answer: By "divestiture by the Federal government from the plight of the mentally ill and their families," I meant the steady, observable withdrawal of federal responsibility and leadership vis-a-vis mentally ill citizens. The ADM Block Grant, with one stroke, repealed the Mental Health Systems Act -- a product of federal responsibility and leadership so sorely needed. The wholesale cutting off of mentally ill beneficiaries from the SSI and SSDI roles between 1982 and 1984 continued the divestiture. There has been a divestiture in the failure of Congress this past decade to provide funding level with inflation into the causes and treatment of mental illness.

2. If we had had strong Federal leadership and a good system of community care and assistance to families at the time your son first became ill twelve years ago, what difference would it have made to your son and your family.

Answer: If the Federal government had been funding research on the major mental illnesses as a priority, our family may have escaped being labeled the causative factor of our son's illness. This is a trauma no family should be called upon to endure. Research, which is still greatly underfunded, has in the last few years demonstrated convincingly that the most serious mental illnesses are caused by diseases of the brain. Strong federal leadership, particularly in designating monies for research, would go a long way in addressing the devastating stigma our family and our son has had to face.

3. Isn't it true that chronic mental illness can strike at virtually any family?

Answer: Yes. It knows no racial, ethnic, class, geographic, or sex limits.

4. As you look to the future, what do you fear most?

Answer: I fear that after we, the parents, die my son may not get the care he needs in order to realize the most out of his limited life. I fear for others who may not be the beneficiaries of a system of community care because society was never able -- whether because of tight budgets, stigma, or indifference -- to provide an adequate care system for its mentally ill citizens. In spite of the pinch for public dollars and those people who would sweep mentally ill persons back behind the walls of our state hospitals, I hope there is enough time to alert society to its responsibilities to provide quality care in the community for these less fortunate citizens.

5. What is the most important single action you would like to see this Committee take?

Answer: The Committee can become an active forum for mental health/mental illness issues. It ought to be staffed with experts in this area. It ought to hold hearings and issue reports and be a single place where those who are concerned with the great national burdens of mental illness, alcoholism, and drug abuse might look for leadership, legislative ideas, and education.

The CHAIRMAN. Let me just ask a few questions. I would like to put some questions in writing to each of you, if you would respond to the committee.

Mrs. Lagomarsino, let me ask you a question first. In your opinion, what is the greatest concern a parent faces with a chronic mentally ill child? That is a tough question, but I would like to have you respond to that, if you can. Help us all.

Mrs. LAGOMARSINO. The toughest?

The CHAIRMAN. That you would think the toughest, the toughest problem or concern that you would face as a parent.

Mrs. LAGOMARSINO. In the beginning, it is realizing in fact that you have a mentally ill son, and then the second is making him believe it. That takes a lot of years of getting through to each of you.

The CHAIRMAN. Could I ask one other additional question. What kind of barriers did you face which prevented you from seeking appropriate treatment for your son?

Mrs. LAGOMARSINO. That he would not cooperate, because he did not believe that he was mentally ill—or, if he believed it, it was that not wanting to believe it. And maybe the diagnosis did not come soon enough. It was just that he had some deep psychological problems, but they could be worked out, so you would go along with the psychotherapy. But then, it was not until medication and the monitoring of the medication—which has to be closely monitored, because all medications do not affect everybody the same way—so it is constant, constant help.

But the toughest thing is realizing that he is mentally ill and accepting it and getting on with the program.

[Information supplied for the record follows:]

WHAT KIND OF BARRIERS DID YOU FACE WHICH PREVENTED YOU FROM SEEKING APPROPRIATE TREATMENT FOR YOUR SON?

The first problem was that he would not cooperate because he did not believe that he was mentally ill—or, if he believed it, it was that he didn't want to believe it. Second, the diagnosis did not come soon enough. We thought it was just that he had some deep psychological problems, but they could be worked out so we all went along with the psychotherapy. The point is that because of the stigma associated with mental illness, it takes too long for everyone concerned to realize that it is an illness which, in most cases, must be treated with closely monitored medication.

The CHAIRMAN. Thank you.

Dr. Frazier, the alcohol, drug abuse and mental health services block grant provides for a priority funding of services for the chronic mentally ill through community mental health centers. How much do you know about the extent to which the States are carrying out this priority? Do you feel they are doing a good job? Do you feel that we have set it up right? Have we written the legislation correctly—because we have really worked hard on that. While there is not a lot of money there, it is money authorized for important programs.

Dr. FRAZIER. Yes, Senator. Since the implementation of the ADMS block grants, the majority of the States have designated the chronic mentally ill as the priority population to receive services under the block grant. We are just beginning to receive data collected from the various States, but each State reports annually what it is doing with the money, and they have indicated that community mental health centers are now serving more chronic mentally ill patients. There is an increased census of chronic mentally ill persons at community mental health centers since the States have made it a priority.

The 1984 amendments to the block grant program required the States to report the different populations who are receiving mental health services in the facilities being supported by the block grant funds. At NIMH we have been working with each of these States to try to develop a uniform reporting system so we can find out the actual number of chronically mentally ill, children and adolescents, and elderly who are coming for help and the kinds of services they are receiving.

The CHAIRMAN. Concerns have been brought to my attention that we may need to put more funds into programs for chronic mentally ill people. Would you please elaborate on the National Institute of Mental Health's funding of research and treatment for schizophrenia and other chronic mental illnesses?

Dr. FRAZIER. Yes. We certainly have been concentrating on chronic mental illness, especially the major psychoses, schizophrenia and major manic-depressive psychoses. We are this year spending $18.4 million on schizophrenia research, $12 million in the extramural program, about $6 million in the intramural program. I have declared it a major priority of the Institute, and it certainly is to me, having spent my life in treating and diagnosing mentally ill children, it is pretty clear that these are major problems.

We have funded a Schizophrenia Research Center at the University of Maryland, under the direction of Dr. Will Carpenter, at the Maryland Psychiatric Research Institute. We also convened a meeting in July which brought together researchers who have been in schizophrenia research, and those who have left the field of schizophrenia research and tried to find out what do we need to do to emphasize schizophrenia as a research priority, and how do we keep people in the field so that there is a critical mass of research scientists.

In addition, NIMH has a collaborative program of five research centers in five different States, having to do with comparing treatments of major psychosis, especially schizophrenia.

We also have a Psychosocial Research Center at Boston University and Albert Einstein Medical College. In addition, we have a great deal of research in major affective disorders.

The CHAIRMAN. Thank you.

In your testimony, you estimate that a majority of individuals suffering from chronic mental illness live with their families, but that that trend is declining.

Dr. FRAZIER. Yes.

The CHAIRMAN. Can you give us what your opinion is as to why this dangerous trend of declination?

Dr. FRAZIER. Well, part of the trend has to do with the fact that the population of chronic mentally ill is becoming younger. There is as that cohort of young adults, who have never been in institutions. It is also true that the families of chronic mentally ill persons believe that sometimes it is not appropriate or beneficial for a young adult who has a chronic mental illness to live in the parental home. These families are becoming a little vocal about the need for residential services, which we have heard Mrs. Krumdieck express that need—alternative facilities are important.

There is also an increasing number of chronic mentally ill young persons who are abusing substances. We do not know the exact number. We have anecdotal data that says about 50 percent. They are like other people in their age group, their peer group, and they use alcohol and drugs which are readily available. Very often they use them for self-treatment. Because of this use of substances, they do not do well in a family setting.

We also have a whole problem of the families of the chronic mentally ill wondering what is going to happen to their offspring as the parents grow older, and worry "After I am gone, what is going to happen?" That is an important issue that we have to help them face. And one way to help face it is to develop alternative residential facilities.

In addition, with the increasing number of divorces, we have a fewer numbers of families available.

The CHAIRMAN. It has been reported from various sources in the mental health field that there is a significant population of young adult chronic patients who have, substance abuse problems. Now, what is the extent of this problem, how are we addressing it, and what should we do?

Dr. FRAZIER. We do not have precise numbers. Anecdotal data indicates that up to 50 percent may have substance abuse problems. We are looking to do something about it. We have a grant with the University of Maryland, the Department of Psychiatry, as well as the Maryland State Department of Mental Health. Under the terms of that award, we are asking them to organize a national task force on the young adult chronic patient with substance abuse problems. And they will look at all the components of ADAMHA's three Institutes, to address this very serious public health problem.

The young adult chronic mentally ill patient who uses substances, alcohol and drugs, like their peers in society do not usually understand that the use and abuse of these substances have a different impact on them due to their mental illness.

The CHAIRMAN. Mrs. Krumdieck, in your testimony, you paint a picture of a mental health system unresponsive to the patients and their families. Now, what suggestions do you have to make these programs more responsive to individual patient and family needs?

Mrs. KRUMDIECK. Well, probably the most important suggestion I would have is that we families have an integral part in the kind of planning that goes on for services. I think Dr. Frazier mentioned some kind of a task force that is coming up Dr. Frazier, are you going to have families on that task force?

Dr. FRAZIER. Surely.

Mrs. KRUMDIECK. That is what is needed.

The CHAIRMAN. She knows how to put you on the spot. [Laughter.]

Dr. FRAZIER. I appreciate it. We need all the help we can get.

Mrs. KRUMDIECK. We families are out there on the front line. We are out there in the trenches, and we have information to give, along with folks like Dr. Frazier. Together we can make a whole picture.

The CHAIRMAN. All right. I am interested in your response here.

Let me just ask you this final question. I think it is intereting to note that at the end of your written testimony, you request more Federal intervention, while your personal experience is one, really, as I read it, of frustration with the mental health system.

Now, where you have met with success was when you mobilized your own resources and those at the local level. So my question is wouldn't more Federal intervention contradict your personal experiences—or are you saying we need to put more Federal money, but not Federal intervention?

Mrs. KRUMDIECK. Well, I guess intervention sort of bothers me, and I did not really mean it from that perspective. I think what I meant more is that I think it is really important for the Federal Government to make some real statements about the fact that we need to wage a war on mental illness, that the Federal Government needs to give a clear message. And then, as I shared with you about putting our housing complex together in Eugene that without section 8 rental subsidy, we could not have put that together. No matter how much work we were willing to do, no matter what agencies we had in Oregon, that had to be the key ingredient.

So I see the Federal Government important in many, many ways.

The CHAIRMAN. Well, I want to thank all three of you for being here. I think you each in your individual ways have been very, very helpful to this committee.

Mrs. Lagomarsino, I think that you have been very courageous to come here. It is typical of you and your husband. I really admire both of you, and I am very grateful that you would do this.

And Dr Frazier, there is just nobody who can articulate what these problems are and what the solutions are better than you, in my opinion—although we are going to try and find some more here before the hearing is over.

And Mrs. Krumdieck, we bave been very interested in your experiences as well.

So we appreciate all three of you being here. Thank you very much.

Mrs. **KRUMDIECK**. Thank you very much.

Mrs. **LAGOMARSINO**. Thank you.

Dr. **FRAZIER**. Thank you very much. We appreciate the opportunity.

[Responses of Mrs. Lagomarsino to questions submitted by Senators Hatch and Kennedy follow:]

Questions for Mrs. Robert (Norma) Lagomarsino; Submitted by Senator Hatch, in regards to hearing on "Barriers to Health Care" October 9, 1985.

1. What can be done to encourage the continued involvement of family in the care of the chronically mentally ill?

4. In your statement, you refer to a need for better monitored administration of federal assistance to chronically mentally ill individuals. Could you elaborate on this suggestion?

1. Community services should insist on family involvement when available and appropriate. You hear of too many cases when the family of a mentally ill individual completely disassociate themselves because they don't know what else to do. They should be guided in their efforts to deal with the family member.

4. There should be responsibilities associated with receiving federal assistance. For example, my son works twenty hours a week with social workers. This experience is training him how to live in the real world. You can't have it both ways. If you are going to receive federal assistance then you have a responsibility to work at getting well. All too often, retroactive federal assistance arrives in the form of a large check. There is no system to insure that the money is used for its intended purpose. I know of one case where a check was received in the amount of $650. The individual spent it within one day at a casino and returned home to harass and threaten his mother for $10. The point is there must be a system of checks and balances which in the long run, is in the individual's best interest.

Questions for Mrs. Robert (Norma) Lagomarsino; Submitted by Senator Kennedy, in regards to hearing on "Barriers to Health Care" October 9, 1985.

1. Mrs. Lagomarsino, Thank you for your eloquent testimony. You mention that your son's successful release from a state hospital involved a transition to a halfway house and then to a satellite apartment situation before he was able to move to his own apartment. You also mentioned that he continues to see a doctor regularly. Do you think the existence of these intermediate steps between hospitalization and independence has been crucial to his recovery? Do you think that it is important that this kind of a continuum of care be available to every patient who needs it?

2. As a mother, I know this must have been a terribly difficult and heart-rendering experience. What kind of support was most important to your family and what do you feel was most lacking or difficult to obtain?

1. Yes. Of course However, there is a need for even more facilities where structured living is possible If the stigma was erased, neighborhoods would be more willing to accept such facilities.

2. I spoke on this subject in response to one of the questions Senator Hatch asked me at the hearing

The CHAIRMAN. At this time, I am pleased to introduce our second panel. First, I would like to introduce a personal friend of mine, Dr. Russell Williams, who is the executive director of the Davis County Mental Health Center.

Russ, I am really pleased to welcome you here today and would like to particularly congratulate you on becoming the president-elect of the National Council of Community Mental Health Centers. I think that is a real tribute to our State and certainly to you as well.

I look forward to your testimony and your insights into services for the chronic mentally ill within our State of Utah.

Second, I would like to introduce to you Dr. John Talbott, who is professor and chairman of the Department of Psychiatry at the University of Maryland.

Dr. Talbott, we are honored to have you here today. We welcome you to the committee, and we are looking forward to hearing your testimony.

Again I would like your oral testimony limited to 5 minutes. We are going to put both of your written statements in the record. That will help me to have a little more time for questions which have arisen as a result of the testimony that we have read.

Dr. Williams, let us turn to you first.

STATEMENT OF DR. RUSSELL A. WILLIAMS, EXECUTIVE DIRECTOR, DAVIS COUNTY MENTAL HEALTH CENTER, FARMINGTON, UT; AND DR. JOHN A. TALBOTT, PROFESSOR AND CHAIRMAN, DEPARTMENT OF PSYCHIATRY, AND DIRECTOR, INSTITUTE OF PSYCHIATRY AND HUMAN BEHAVIOR, UNIVERSITY OF MARYLAND, BALTIMORE, MD

Dr. WILLIAMS. Mr. Chairman and members of the committee, I am Dr. Russell Williams, executive director of the Davis County Comprehensive Mental Health Center. I am also president-elect of the National Council of Community Mental Health Centers, which represents over 600 community mental health centers nationwide.

The National Council commends you, Mr. Chairman, for holding these hearings, addressing barriers to health care. We especially appreciate your longstanding commitment and hard work in seeking to assure that the needs of the mentally ill, including those individuals experiencing alcohol and drug abuse problems, are met.

Mr. Chairman, in recent years, we in Utah, along with the entire community mental health system, have been forced to reassess our future. Federal funding involvement has been substantially reduced; deinstitutionalization has continued. There are a growing number of young people who are seriously mentally ill. Moreover, Mr. Chairman, one of the tragedies we face is the burgeoning number of individuals with serious chronic mental illness.

These factors and others have placed a great deal of pressure on the existing community mental health system.

Congress envisioned in 1963 that after the establishment of community mental health centers throughout the country, that ongoing funding for these programs and services would come from such primary sources as Medicare, Medicaid, and other third-party payors. We all know that these well-motivated intentions have not come to fruition.

The community mental health system has had to overcome these and other barriers. However, the system has demonstrated remarkable resilience in its ability to deliver services to an ever-growing number of persons in need.

The key areas that still must be addressed within the community mental health system include: The development of a coordinated Federal, State, and local strategy to meet the full range of service needs of the chronic mentally ill; the expansion of services to unserved areas and underserved populations; the expansion of Medicaid, Medicare, and other third-party reimbursements to cover a larger portion of mental health care, and to look at the stigma in our local communities which create significant obstacles to effective treatment.

I understand that legislation has been introduced by Senator Kennedy which would address some of the service issues just discussed, and we look forward to reviewing his pending legislation.

We of course would like to continue to work with you, Mr. Chairman, Senator Kennedy, and other members of the committee on this and other legislation to develop innovative and cost-effective approaches to better serve the chronically mentally ill, as well as all persons in need of mental health services throughout the country.

However, Mr. Chairman, it is important to note that the community mental health system has been forced to operate within limited resources; while new initiatives are needed, funding for them must not jeopardize existing services.

Additional resources, not a redistribution or reprioritization of limited funding are required.

Mr. Chairman, I would like to summarize for the committee what we at Davis County Mental Health Center do to meet the broad range of mental health needs of the mentally ill.

The Davis County Mental Health Center is a comprehensive community mental health center with a full range and complement of services. The continuum of services offered by the center provide those in need of mental health treatment with an integrated and coordinated service delivery system at the community level that can be tailored to the specific needs of an individual. This is especially important for those persons suffering from severe mental illness because they require a range of services that continually shift and involve services outside the traditional mental health treatment. These services are often called community support services.

Although aftercare and followup and transitional residential care services are an integral part of the Davis County Mental Health Center's delivery system, external financing for these services is more limited and generally more difficult to obtain than the funding for some of the other services offered. These services do not fall neatly into the various present funding mechanisms. For example, Mr. Chairman, we can place a patient in a psychiatric inpatient unit at a cost of between $250 and $300 per day and receive third-party reimbursement. However, if the individual is transferred to a more clinically appropriate and less restrictive transitional residential program at an approximate cost of $90 per day, there is no third-party reimbursement, such as Medicaid. available, because of the Institution for the Mentally Diseased [IMD] barrier and other barriers that are present in the third-party payor system.

Mr. Chairman, the State of Utah has demonstrated its concern and commitment to those residents of Utah who are suffering from mental illness by establishing a comprehensive mental health system. Under the State, local, and Federal partnership, in 1979, Utah became the first State in the Nation to expend a larger portion of its available resources for community-based programs than for institutional care.

Providing appropriate care to the mentally ill residents of the State of Utah in the least restrictive environment is an important concept that is still in progress. As has been demonstrated, the comprehensive community mental health system is working. However, as described earlier, there is still much to be done.

In closing, I would again like to thank you, Mr. Chairman, for allowing us this opportunity to testify, and would be pleased to answer any questions.

[The prepared statement of Dr. Williams and responses to questions submitted by Senators Hatch and Kennedy follow:]

NATIONAL
COUNCIL OF
COMMUNITY
MENTAL
HEALTH
CENTERS

STATEMENT ON
BARRIERS TO HEALTH CARE
THE CHRONICALLY MENTALLY ILL

PRESENTED BY:

RUSSELL A. WILLIAMS, PH.D.
EXECUTIVE DIRECTOR
DAVIS COUNTY MENTAL HEALTH CENTER
FARMINGTON, UTAH

ON BEHALF OF:

THE NATIONAL COUNCIL OF COMMUNITY MENTAL HEALTH CENTERS

BEFORE:

COMMITTEE ON LABOR AND HUMAN RESOURCES
U.S. SENATE

OCTOBER 9, 1985

6101 Montrose Road Suite 360 Rockville MD 20852 (301) 984-6200

Mr. Chairman and members of the Committee, I am Russell Williams, Executive Director of the Davis County Mental Health Center, which is located in Farmington, Utah. I am also the President Elect of the National Council of Community Mental Health Centers, which represents over 600 community mental health agencies nationwide.

Mr. Chairman, in recent years we in Utah, along with the entire community mental health system, have been forced to reassess our future. Federal funding has been substantially reduced. The enactment of the Alcohol, Drug Abuse and Mental Health Block Grant has limited federal involvement in the delivery of mental health services, while state governments' responsibilities regarding the administration and provision of community mental health services has grown. Deinstitutionalization has continued. There are a growing number of young people who are seriously mentally ill and desperately in need of mental health services. Moreover, Mr. Chairman, one of the tragedies we face is the burgeoning number of individuals with serious chronic mental illness whose needs must be met. These factors and others have placed a great deal of pressure on the existing community mental health system.

As you know, Mr. Chairman, in 1963, Congress passed legislation that created community mental health centers. At that time, Congress intended for every citizen to have access to comprehensive mental health services, regardless of their ability to pay. Congress also envisioned in 1963 that, after the establishment of community mental health centers throughout the

COUNTRY, THE ONGOING FUNDING FOR THESE PROGRAMS AND SERVICES WOULD COME FROM SUCH PRIMARY SOURCES AS MEDICARE, MEDICAID AND OTHER THIRD-PARTY PAYORS. WE ALL KNOW THAT THOSE WELL-MOTIVATED INTENTIONS HAVE NOT COME TO FRUITION. APPROXIMATELY 50% OF AMERICAN CITIZENS STILL DO NOT HAVE ACCESS TO MENTAL HEALTH SERVICES, AND MEDICARE, MEDICAID AND THIRD-PARTY PAYORS REMAIN A VERY SMALL PART OF MENTAL HEALTH FUNDING AT ALL LEVELS.

THE COMMUNITY MENTAL HEALTH SYSTEM HAS HAD TO OVERCOME THESE AND OTHER BARRIERS AND THE SYSTEM HAS DEMONSTRATED REMARKABLE RESILIENCY IN ITS ABILITY TO DELIVER SERVICES TO AN EVER-GROWING NUMBER OF PERSONS IN NEED. YOU, MR. CHAIRMAN, OF COURSE, KNOW THIS FROM OUR UTAH EXPERIENCE. HOWEVER, MUCH REMAINS TO BE DONE TO ASSURE THAT THOSE MILLIONS OF CLIENTS WHO REMAIN IN NEED OF MENTAL HEALTH CARE ARE ABLE TO ACCESS THAT CARE. THE KEY AREAS THAT STILL MUST BE ADDRESSED WITHIN THE COMMUNITY MENTAL HEALTH SYSTEM INCLUDE: THE DEVELOPMENT OF A COORDINATED FEDERAL, STATE AND LOCAL STRATEGY TO MEET THE FULL RANGE OF SERVICE NEEDS OF THE CHRONICALLY MENTALLY ILL; THE EXPANSION OF SERVICES TO UNSERVED AREAS AND UNDERSERVED POPULATIONS; EXPANSION OF MEDICARE, MEDICAID AND OTHER THIRD-PARTY REIMBURSEMENTS TO COVER A LARGER PORTION OF MENTAL HEALTH CARE; IMPROVED HOUSING OPPORTUNITIES FOR THE CHRONICALLY MENTALLY ILL; INCOME SUPPORT; AND THE ALLEVIATION OF STIGMA IN OUR LOCAL COMMUNITIES WHICH CREATE SIGNIFICANT OBSTACLES TO EFFECTIVE TREATMENT, SUCH AS ZONING ORDINANCES THAT LIMIT ACCESS TO APPROPRIATE HOUSING. WE ARE ALL VERY AWARE THAT THESE ARE NOT THE BEST OF ECONOMIC TIMES, BUT THOSE PERSONS SUFFERING FROM CHRONIC MENTAL ILLNESS ARE THE LEAST ABLE TO COPE

IN SUCH TIMES, AND MUST NOT BE FORGOTTEN.

I UNDERSTAND THAT LEGISLATION HAS BEEN INTRODUCED BY SENATOR KENNEDY WHICH WOULD ADDRESS SOME OF THESE SERVICE ISSUES JUST DISCUSSED. THE NATIONAL COUNCIL APPRECIATES SENATOR KENNEDY'S LONG-STANDING INTEREST IN ADDRESSING THE SERVICE NEEDS OF THE CHRONICALLY MENTALLY ILL AND WE LOOK FORWARD TO REVIEWING HIS RECENTLY INTRODUCTED LEGSILATION AT THE NATIONAL COUNCIL'S UPCOMING BOARD OF DIRECTORS MEETING. WE, OF COURSE, WOULD LIKE TO WORK WITH THE COMMITTEE ON THIS AND OTHER LEGISLATION TO DEVELOP INNOVATIVE AND COST-EFFICIENT APPROACHES TO BETTER SERVE THE CHRONICALLY MENTALLY ILL, AS WELL AS ALL PERSONS IN NEED OF MENTAL HEALTH SERVICES THROUGHOUT THE COUNTRY. HOWEVER, MR. CHAIRMAN, IT IS IMPORTANT TO NOTE THAT THE COMMUNITY MENTAL HEALTH SYSTEM HAS BEEN FORCED TO OPERATE WITHIN LIMITED RESOURCES. WHILE NEW INITIATIVES ARE NEEDED, FUNDING FOR THEM MUST NOT JEOPARDIZE EXISTING SERVICES. ADDITIONAL DOLLARS, NOT A SHIFTING OF RESOURCES, ARE REQUIRED.

MR. CHAIRMAN. I WOULD NOW LIKE TO SUMMARIZE FOR THE COMMITTEE HOW WE AT THE DAVIS COUNTY MENTAL HEALTH CENTER ATTEMPT TO MEET THE BROAD RANGE OF MENTAL HEALTH NEEDS OF THE CHRONICALLY MENTALLY ILL.

THE DAVIS COUNTY MENTAL HEALTH CENTER IS A COMPREHENSIVE COMMUNITY MENTAL HEALTH CENTER WITH A FULL RANGE AN COMPLIMENT OF SERVICES EXTENDING FROM PREVENTION, EDUCATION AND CONSULTATION ON ONE END OF THE TREATMENT/SERVICE SPECTRUM, THROUGH 24-HOUR HOSPITAL-BASED INPATIENT CARE AT THE OTHER. OUR AGENCY HAS AS ITS BASIC PURPOSE OR MISSION, THE PROMOTION AND ENHANCEMENT OF

THE MENTAL HEALTH OF THOSE RESIDING WITHIN ITS SERVICE AREA. THE EFFORTS OF THE CENTER ARE SPECIFICALLY DIRECTED TOWARD ASSISTING THOSE WHO ARE ADVERSELY AFFECTED BY A SIGNIFICANT DEGREE OF PSYCHOLOGICAL IMPAIRMENT AND WHOSE GENERAL ABILITIES TO FUNCTION AS PRODUCTIVE INDIVIDUALS AND MEMBERS OF THEIR FAMILY AND COMMUNITY ARE SERIOUSLY DIMINISHED. IT IS THE GOAL OF THE DAVIS COUNTY MENTAL HEALTH CENTER TO PROVIDE THESE INDIVIDUALS WITH EFFECTIVE, APPROPRIATE PROFESSIONAL CARE AND SERVICES DESIGNED TO ELIMINATE, REDUCE OR AMELIORATE THE EFFECTS OF MENTAL ILLNESS. THE SERVICES THAT ARE MADE AVAILABLE BY THE CENTER INCLUDE: OUTPATIENT, 24-HOUR EMERGENCY SERVICE, PARTIAL HOSPITALIZATION/DAY TREATMENT, CONSULTATION, PREVENTION/ EDUCATION, SCREENING/ASSESSMENT, TRANSITIONAL, AFTERCARE AND FOLLOW-UP SHORT-TERM AND LONG-TERM INPATIENT, AND DRUG AND ALCOHOL ABUSE SERVICES. ANOTHER IMPORTANT COMPONENT OF OUR COMPREHENSIVE SERVICE DELIVERY SYSTEM IS THE UTAH STATE HOSPITAL WHICH PROVIDES LONG-TERM PSYCHIATRIC INPATIENT CARE FOR THOSE INDIVIDUALS WHO NEED A MORE STRUCTURED ENVIRONMENT THAN CAN BE PROVIDED FOR IN THE COMMUNITY.

THE CONTINUUM OF SERVICES OFFERED BY THE DAVIS COUNTY MENTAL HEALTH CENTER PROVIDES THOSE IN NEED OF MENTAL HEALTH TREATMENT WITH AN INTEGRATED AND COORDINATED SERVICE DELIVERY SYSTEM AT THE COMMUNITY LEVEL THAT CAN BE TAILORED TO THE SPECIFIC NEEDS OF AN INDIVIDUAL. THIS IS ESPECIALLY IMPORTANT FOR THOSE PERSONS SUFFERING FROM SERIOUS MENTAL ILLNESSES BECAUSE THEY REQUIRE A RANGE OF SERVICES THAT CONSTANTLY SHIFT AND INVOLVE SERVICES OUTSIDE OF TRADITIONAL MENTAL HEALTH TREATMENT SUCH AS HEALTH care, housing, income support, employment counseling, and social services. It is these indirect types of services that are essential to building independence for those persons suffering from serious mental illness. These services are often called "community support services." The Davis County Mental Health Center provides several services that could fall under this general category. The key community support-type services provided by our Center include partial hospitalization/day treatment, aftercare and follow-up, and transitional/residential services.

The first prong of the community support system at the Davis County Mental Health Center is partial hospitalization. The purpose of the partial hospitalization/day treatment service is to provide a corrective therapeutic experience which considers the total patient. These services are for individuals who require less than 24-hour-a-day care, but more than outpatient. The goal is to assist the patient in day-to-day functioning while encouraging psychosocial growth and development. Thus, appropriate treatment and learning experiences are provided during evenings and weekends, as well as on a regular daily basis.

The second component of the community support system is aftercare and follow-up services. Aftercare and follow-up services are key to ensuring that gains made by clients in treatment are maintained following discharge from a mental health facility or program Through follow-up care, the opportunities for humanizing the service delivery system within the service area are enhanced and promoted. It is also essential to provide an advocacy service in order to assure patients' rights as they make a reentry and adjustment into the community. Care is taken to see that the dignity of each person is maintained and that social isolation is avoided following treatment.

The third component of the Davis County Mental Health Center's community support program is transitional/residential services. The objective of the transitional service is to provide adequate sheltered community living arrangements for patients discharged from mental institutions, as well as for those who would require such services in order to prevent inpatient hospitalization. A broad array of medical, supportive and rehabilitative services are made available for recipients of transitional care. This service is coordinated with other partial hospitalization services to provide a full range of resources for the client. Since living arrangements of the transitional service are designed to foster a gradual, phased return to community living to the maximum extent possible for each admitted patient, there lso a close coordination with the follow-up service program.

Although aftercare an follow-up and transitional care services are integral parts of the Davis County Mental Health Center's delivery system, external financing for these services is more limited and generally more difficult to obtain than funding for some of the other services offered. These services do not fall neatly into the various present funding mechanisms. For example, resources and facilities are currently inadequate to

MEET THE NEED FOR TRANSITIONAL AND RESIDENTIAL SERVICES FOR CHILDREN AND YOUTH. COMMUNITY-BASED, NON-HOSPITAL RESIDENTIAL TREATMENT FOR ADOLESCENTS AND CHILDREN IS VITAL IN ORDER TO PROVIDE EARLY INTERVENTION AND TO FACILITATE THE APPROPRIATE INVOLVEMENT OF FAMILY, CHURCH, SCHOOLS AND OTHER COMMUNITY SUPPORT SYSTEMS. AS A CONSEQUENCE OF RESTRICTED RESOURCES FOR THESE TYPES OF SERVICES, TOO OFTEN DISTURBED YOUTH DO NOT RECEIVE APPROPRIATE CARE UNTIL THEIR CONDITION REQUIRES MORE INTENSIVE INPATIENT HOSPITAL-BASED TREATMENT OR THEY BECOME INVOLVED WITH THE JUVENILE JUSTICE SYSTEM. THESE DEVELOPMENTS COULD FREQUENTLY BE AVOIDED MORE ADEQUATE RESOURCES WERE MADE AVAILABLE FOR NEEDED SERVICES.

IT IS ALSO DIFFICULT TO OBTAIN ADEQUATE FUNDING FOR THE MYRIAD OF SERVICES OFFERED AS PART OF THE AFTERCARE AND TRANSITIONAL PROGRAM. MR. CHAIRMAN, AS YOU KNOW, THERE IS AN EXISTING PROGRAM ADMINISTERED BY THE NATIONAL INSTITUTE OF MENTAL HEALTH KNOWN AS THE COMMUNITY SUPPORT PROGRAM. THIS PROGRAM PRESENTLY HAS MINIMAL IMPACT ON PROGRAMS SUCH AS THE DAVIS COUNTY MENTAL HEALTH CENTER'S AFTERCARE AND FOLLOW-UP AND TRANSITIONAL/ RESIDENTIAL PROGRAMS. IF FUNDS FOR THIS PROGRAM WERE MORE DIRECTED TO THE LOCAL LEVEL, DEVELOPMENT OF LOCAL COMMUNITY SUPPORT PROGRAMS WOULD BE SIGNIFICANTLY ENHANCED. FOR EXAMPLE, ONLY APPROXIMATELY 30% OF THE TOTAL NIMH COMMUNITY SUPPORT PROGRAM MONIES AVAILABLE IN THE STATE OF UTAH HAVE BEEN ALLOCATED FOR USE AT THE LOCAL LEVEL, AND VERY LITTLE OF THESE FUNDS HAVE BEEN MADE AVAILABLE TO SUPPORT DIRECT SERVICES. CSP DOLLARS THAT HAVE BEEN RECEIVED AT THE LOCAL LEVEL IN DAVIS COUNTY (approximately $1,000 each year) have been used to assist in the formation and development of a patient operated thrift store. Staff support and involvement with this project has had to be covered entirely from other resources. Community Support Program funds have only defrayed approximately 10% of the actual costs.

Mr. Chairman, the State of Utah has demonstrated its concern and commitment to its residents by addressing the needs of those who are experiencing alcohol and drug addiction and mental illness by establishing a comprehensive community mental health system. Under the state, federal and local partnership, Utah has developed a statewide community mental health service delivery system that is directly available to 95% of its residents. In 1979, Utah became the first state in the nation to expend a larger proportion of its available alcohol and drug addiction and mental health resources for community-based programs than for institutional care, thus, reinforcing Utah's commitment to provide appropriate care to the residents of the state in the least restrictive environment. As is demonstrated in the State of Utah, the comprehensive community mental health system is working, and Utah is more fortunate than many other states in this regard.

In closing, I want to thank you, Mr. Chairman, for giving me this opportunity to appear before you today. I would be pleased to answer any questions that you have at this time.

Questions for Dr Russell Williams, Submitted by Senator Hatch, in regards to hearing on "Barriers to Health Care" Octobr 9, 1985.

1. Dr Williams, within the limited resources presently available, what kinds of effective approaches could be developed to better serve the chronically mentally ill?

As has been evidenced in several successful programs throughout the Country, the instigation of a comprehensive continuum of care at the local level provides a greatly expanded resource for meeting the needs of the mentally ill, including the chronically mentally ill, by redistributing limited resources from institutional care to a comprehensive continuum of care at the local level where adequate support systems such as community, family, church, and service groups can serve as a great resource. This fact was testified to by other witnesses and is one that has proven to be effective. By providing a comprehensive continuum of services at the local level, you can shift resources currently being used in institutions to the local level and provide services at a greatly reduced cost, thus serving an increased number of individuals at no additional cost. There are those, however, regardless of our efforts and ability, who still need long-term hospital care and there are also those who need long-term care in a nonhospital based setting. It would also be very helpful if we could utilize limited resources to provide alternate residential care sometimes referred to as institutions for the mentally diseased (IMD), instead of being forced to admit people to psychiatric inpatient units at an inflated cost in order to access third party reimbursement.

Regarding the community support program, limits need to be established on the percentage of community support revenues that can be spent for indirect services at the state level. Currently the majority of this much needed resource is being spent for administrative costs or for program development costs. In my opinion, at least 95% of the revenue needs to be passed onto local based programs for direct services, so that those individuals in need can maximize their opportunities for involvement and have access to treatment.

Questions for Dr Russell Williams, Submitted by Senator Kennedy, in regards to hearing on "Barriers to Health Care" October 9, 1985.

1. Dr. Williams, would you agree that restrictions on medicaid's ability to reimburse for community-based care have been a significant barrier to an effective system of care for the chronically mentally ill.

2. There seems to be a relatively well-established community-based system of care for the chronically mentally ill in Utah. As we look across the country as a whole, isn't it true that such systems are often sadly lacking? Doesn't the Federal government which provides approximately 45% of the funding for the chronically mentally ill have a responsibility to assure the existence of a humane, effective, community-based system of care throughout the country?

1. As was stated in my te [illegible] nd also in response to questions submitted by Senator Hatch, the cu. [illegible] 's inability to recognize community based comprehensive care programs to provide at least as effective and in some cases more effective clinical treatment in nonhospital based residential programs has been a significant barrier to an effective system of care for the mentally ill, including the severely chronically mentally ill. It needs to be emphasized that a comprehensive continuum of care for all individuals experiencing mental illness is essential. Certainly children and youth who are experiencing mental illness are deserving of appropriate timely care especially during these formative years. It would also seem equally important to address the needs of women as a deserving population, and because of their role as mothers and their responsibility in child rearing as well as meeting the needs of the severely chronically mentally ill.

2. In my opinion, the locally based comprehensive continuum of care approach to meeting the needs of the mentally ill has proven to be most effective in those areas where such services are available. I also feel it would be in the best interest of not only the mentally ill, but to our Country to have available such services across our nation so that individuals would have equal access to treatment regardless of place of residency. One of the strong points of the development of such a system in Utah has been the Federal, State and local partnership working together with private industry and citizens of the State of Utah in an effort to deal with individuals in their time of need. I feel the Federal Government should be a partner in helping develop such needed services. Great care should be taken in helping individuals to become self-sufficient and self-directing in all cases possible and not to develop inappropriate dependencies or foster unhealthy lifestyles. It is very important that we recognize the mental health needs of all individuals and not try to resolve the unmet needs of the severely chronically mentally ill by a reauthorization or redistribution of limited resources.

The CHAIRMAN. Thank you, Dr. Williams. I am pleased with your testimony, and we will see what we can do to work on some of the problems that you have mentioned here today. I think they are significant. As you have pointed out to me in the past, perhaps some of us have not realized some of these problems. So your testimony is very important.

Dr. Talbott, let us turn to you.

Dr. TALBOTT. Thank you very much, Mr. Chairman.

I would like to express also our appreciation to you for holding today's hearing on the important matter of the chronic mentally ill, at the same time as Mental Illness Awareness Week is being held.

My name is John A. Talbott, M.D. I am the immediate past president of the American Psychiatric Association, an association of over 30,000 specialists in psychiatry across the country. I am also professor and chairman of the department of psychiatry at the University of Maryland. As Dr. Frazier mentioned earlier, it is the University of Maryland in the State of Maryland that conduct the Schizophrenia Research Program and the study on the young chronic mental patient with drug abuse. I and we in Maryland are in contact with the chronic mentally ill daily.

The scandals that have been created by the unplanned depopulation of the Nation's State hospitals over the past 30 years have really been enormous and well-documented in the press, and have been nationwide. We are all familiar with the high incidence of serious mental illness among the homeless, mentioned earlier, up to 50 percent; the ongoing nursing home scandals and the increased population of the mentally ill in jails and prisons across our Nation.

I would like to concentrate on five different points today, though, in terms of the current care and treatment of the chronic mentally ill. First, the point that deinstitutionalization was a failure not so much in its concept but in its implementation. Second, that part of this failure had to do with the inability to move the umbrella of care from the single locus, the State hospital, to the community. Third, that the responsibility for individual patients was lost in the multiplication of services during deinstitutionalization. Fourth, the need for an appropriate range and adequate number of services, and fifth, the difficulty with fragmentation in governmental reponsibility.

Now, with your permission, I would like to use some of my contacts with individual patients and patients' families as an illustration of that point, because I think such examples, as you heard earlier today, really clearly illustrates the problems.

First, in the failure of deinstitutionalization's implementation rather than conception, a patient just this week talked to me about how much more he enjoyed being in the community, receiving community services, being able to do what he wanted to do, but wishes he had the same services—medical, psychiatric, dental, social, nursing, et cetera—that he had in the hospital at the time—although be prefers to be outside.

Second, the inability to move all the different services from institutional to community care. Another patient talked to me about the fact that he needed to operate as a scrounging system. Instead of the system of care being comprehensive and available, he himself was required to be the scrounger and to obtain his own services.

Third, in terms of lack of responsibility, moving from a single, responsible place of care to multiple agencies, both institutional and in the community, no one is in charge in many parts of the country—neither a single person for a single patient, nor a single agency for the population. Again, yesterday, a family member of a patient spoke movingly to me about not knowing where to get care, treatment, housing, et cetera, just as we heard this morning.

Fourth, the need for an adequate range and number of settings. Patients cannot go simply from the hospital to living by themselves. They need to have halfway houses, quarter-way house, day hospital care, group homes, foster care, and the like.

Patients complain bitterly of having no place else to go when they leave the hospital, but to either a nursing home or more often to a rotten hotel situation.

And finally, fifthly, the fragmentation of government agencies. As Dr. Frazier reminded us, the mentally ill and the chronic mentally ill all have the same needs we all have, for housing, social services, medical care, rehabilitation, et cetera. But those are each delivered by a different Federal, State, and sometimes even local agency. We must have some way of tying there services together. It is difficult enough for the healthy to negotiate all these systems; it is impossible for those people who are hallucinating, delusional, and have difficulty thinking.

Again, just this week, a patient was talking about how hard he struggled trying to deal with the bureaucracies he had to deal with, without having them be responsive to his needs

The solutions to these five different issues, I think, are clear. In implementing deinstitutionalization, we need a plan and a rebalancing of services. For the umbrella, we need to have a comprehensive system of care. For responsibility, we need individuals to be responsible for individual and an agency to be in charge of the patent population and to provide continuity. And we need an adequate range and number of services and a mechanism to provide those. And finally, coordination at Federal, State, and local levels, in order to coordinate both services and funding streams.

Mr. Chairman, again I thank you for the opportunity of appearing here today. I think the issues that are being raised by you and the committee are terribly important. We are most pleased that Congress has recognized the importance of chronic mental illness with this third year of observance of Mental Illness Awarness Week.

Thank you, Mr. Chairman.

The CHAIRMAN. Thank you so much.

[The prepared statement of Dr. Talbott and responses to questions submitted by Senators Hatch and Kennedy follow:]

TESTIMONY

John A. Talbott, M.D.
Professor and Chairman
Department of Psychiatry
Director of the Institute of Psychiatry and
Human Behavior, University of Maryland

on

The Chronically Mentally Ill

before the

Senate Labor and Human Resources Committee

October 9, 1985

Mr. Chairman and distinguished members of the subcommittee, my name is John Talbott, M.D. I am Professor and Chairman of the Department of Psychiatry at the University of Maryland, immediate past President of the American Psychiatric Association, and have chaired the APA's Ad Hoc Committee on the Chronic Mental Patient. I am particularly proud that the American Psychiatric Association, a medical speciality society representing over 30,000 psychiatrists nationwide, has been in the forefront of increasing involvement and concern by not only the medical profession but all segments of our society about the plight of the chronically mentally ill.

We are gratified that the media attention and emphasis on homelessness or lack of shelter per se among the mentally ill homeless has not deflected this Committee's attention to and concern about the basic, underlying problem of the lack of a comprehensive support system for the severely and chronically mentally ill.

Traditionally the chronic and severely mentally ill of this nation have been cared for in state mental hospitals. From the early 19th century until 1955, the population in these institutions grew steadily. In 1955 due to a variety of circumstances - political, economic, philosophic and therapeutic - the population of the chronically mentally ill in state hospitals began to drop. Nationwide it has fallen from a high of approximately 560,000 in 1955 to under 130,000 in 1985 - a decrease of over three-fourths! At this point in the depopulation process, only 126,000 of the estimated 1.7-2.4 million Americans suffering from chronic mental illness now reside in state facilities.

Yet, in many states, like New York, 80-90% of mental health funding remains directed to the state mental hospitals. While an unknown number of the chronic mentally ill live at home, at least three-quarters of a million are in nursing homes, which are ill-equipped to provide psychiatric services and neither mandated nor funded to do so The remaining 800,000-1,400,000 are in a variety of other settings, including jails and prisons, unsupervised community residences, and the streets themselves, all of which have virtually no services available.

This drop in the census of state facilities was euphemistically called "deinstitutionalization" and consisted of two parts - first, the discharge of thousands of severely and chronically ill citizens from state hospitals into "the community," and second, the refusal to admit many patients, who were often elderly and chronically ill, to the state hospitals.

In fact, Mr. Chairman, the term deinstitutionalization is a misnomer, since the percentage of Americans in institutions has not changed over the past 30 years since (deinstitutionalization) began. While the percentage of persons in state hospitals has dropped by two-thirds, that in nursing homes has trebled. As I stated previously, there are many diverse places where the chronically mentally ill can now be found--in nursing homes, jails and prisons, or unsupervised community residences--and the more correct phrase now is "trans-institutionalization." Whatever it is called, however, the net result of the "movement" was to change the residence of thousands of Americans from one lousy institution to multiple wretched ones. Conceptually, deinstitutionalization was not flawed; its implementation was. With the advantage of hindsight, we can see that the era of deinstitutionalization was ushered in with much naivete and many simplistic notions about what would become of the chronically and severely mentally ill. The importance of psychoactive medication and a stable source of financial support was perceived, but the importance of developing such fundamental resources as supportive living arrangements was not so clearly seen nor implemented. The concept of community treatment was much discussed, but there were no clear ideas as to what it should consist of, and the resistance of community mental health centers and other more traditional providers - of both treatment and social and environmental support services - was not anticipated. Nor was it foreseen how reluctant many states would be to allocate funds for community-based services.

In the state hospitals, what treatment and services that did exist were in one place and under one administration. In the community, the situation is very different. Services and treatment are under various administrative jurisdictions and in various locations. Even the mentally healthy have difficulty dealing with the number of bureaucracies, both governmental and private, in order to have their needs met. Further, patients can easily get lost in the community as compared to the hospital. Imperfectly conceived, deinstitutionalization has led to a situation in which those who have been released from the hospital have fallen between the cracks of the community's social and health service networks. In a sense the refugees from yesterday's back wards have become the inhabitants of our current back alleys. Their asylum--their safe haven--has been lost.

Since the time of mass deinstitutionalization in the 1950s and 1960s, however, other individuals, also chronically mentally ill, whose histories have been vastly different from those who were deinstitutionalized in the early days of the movement, have now entered the system or non-system of the homeless. They have become the victims of the same absent or if not absent, then cumbersome and labyrinthine-like community network, and have not received basic service needs. In the main, this population is younger, more involved with drugs and alcohol, more disruptive, and has a history of short term, rather than long-term hospitalization, based in part upon commitment law changes brought about at the same time as the deinstitutionalization movement. Their lack of shelter is similar to that of those older homeless mentally ill now inhabiting our streets, but their medical, social and other support service needs are vastly different.

By 1985, thirty years after initiation of this massive shift, in which the chronically ill reside, the public outcry was deafening. In cities such as New York, where I resided for almost 30 years, thousands of ex-patients crowd dilapidated ghettoes in the Rockaways, the Bowery, and the Upper West Side - and bag-ladies are as commonplace on Park Avenue as they are on 14th Street or fashionable Connecticut Avenue in the nation's Capital.

While the media have documented the problems of the homeless in general, until re[illegible]ly recently, there has been little attention paid to a very special subgroup within this homeless population--a subgroup whose ranks have been estimated to constitute as many as 50 percent of the homeless-- the homeless mentally ill. While we have all been appalled by the study findings bearing out the surprising numbers of homeless who are characterized as mentally ill, we have, until recently lacked the knowledge of who and, how ill and disabled they are. When we look at the homeless mentally ill, we are really dealing with two problems: homelessness and chronic mental illness. Each in and of itself is a formidable challenge to resolve, but combined, they present a crisis of unprecedented magnitude and complexity.

A DEFINITION OF THE PROBLEM

Who are these people?

I should begin by defining the people I am talking about. The chronically mentally ill are those persons "who are, have been, or might have been, but for the "deinstitutionalization" movement, on the roles of long-term mental institutions, especially state hospitals." They suffer from severe, persistent, or recurrent mental illnesses and have residual social and vocational disabilities. They may have been institutionalized at one time or never hospitalized, but today they reside in both institutional or community settings. The chronicially mentally ill are of all ages, including children, and have a variety of diagnoses. However, they suffer primarily from the major psychoses, e.g. chronic schizophrenia and recurrent affective disorders such as manic-depressive illness.

These patients must be distinguished from those individuals who may be receiving various forms of psychotherapy for mental disorders <u>without</u> attendant long-term disabilities. The chronically ill have a host of special and unique problems including extreme dependency needs, high vulnerability to stress, and difficulty coping with the demands of everyday living, all of which result in their having a great deal of difficulty in holding down a job, securing adequate housing, and obtaining appropriate medical care.

Studies have demonstrated that there are at least 1 million such individuals living outside state hospitals today, and the number may be as high as 5-7 million. While in the early days of deinstitutionalization, the majority of patients discharged from state hospitals returned to their homes, today only a fraction do. One study in California showed that among a group of ex-patients - one-half were living in homes - nursing homes, board and care homes, welfare hotels and the like. In the area of the upper West Side of New York City we estimated that at one time there were approximately 25,000 chronically mentally ill persons living in single room occupancy hotels.

Regarding their illness, one-third have symptoms of severe mental illness and one-third have moderate symptoms. However, fewer than 50% continue their medication and only 25% are in some aftercare program.

As I have mentioned previously, they also have marked residual disabilities. Only 30-50% of discharged patients are able to return to work, and of these 70% return to a less skilled job. After year the number of those employed drops to 20-

30%. In addition only 25% have what we would consider a normal family life - the other 75% live an isolated social existence.

What do they need?

As opposed to those mental patients who suffer from acute mental illnesses such as acute depression, where they may be hosptialized, and when treated and discharged, return to their homes, families and jobs with hardly a step missed, these patients have a host of needs. Because of their illness, they have a lessened ability to think clearly and react to stress normally - and because of their disability they have difficulty getting along with people, working efficiently, or living on their own.

They need an array of housing opportunities, through which they can move gradually from complete institutionalization to completely independent living. Not all will make it all the way, but the opportunities must be present in the form of good hospitals, partial hospitals (day, night and weekend facilities), quarterway and halfway houses, group living homes, foster homes and independent apartments.

They also need sources of income, including part-time employment for those who can work; vocational counseling and rehabilitation for those who may be able to recover some functioning; and income maintenance for those who cannot return to work.

They need social contacts and socialization if they are to return to the mainstream of community life. And critically, since many of the chronically mentally ill have higher incidences of medical illness than the general population, they need access to good medical care.

Last, but not least, they require a different type of psychiatric care than we usually think of. In addition to the sorts of things we regard as essential - e.g., good inpatient

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hospitals, good aftercare clinics and good crisis intervention units - they require a specialized form of rehabilitation that emphasizes the things we all take for granted in living in a complex society: the ability to use a bank or public transportation, groom ourselves well, look presentable at an interview, wash our clothes and use a laundromat, buy our food economically, nutritiously and sensibly, and cook it palatably, etc. These so-called skills in everyday living are the key to restoration of community life, and they are the heart of those programs in this country that have been most successful with the chronically mentally ill.

What programs are successful with these individuals?

We have looked at many programs designed for the chronically mentally ill, both in the hospital and in the community. They are of two basic types - one which is located in the hospital and prepares patients to return to the community, and the second which maintains patients in community settings.

One of the best documented preparatory programs is that described by Gordon Paul, Ph.D. who originally worked at a state hospital in Decatur, Illinois. The feature of this program was that it emphasized resocialization and relearning of the skills of everyday living that I referred to before. Its entire thrust was to return patients to the community with the tools and skills whereby they can function well. And they do. Few returned to the hospital, whereas 30% of those treated with milieu treatment returned, and 50% of those treated on a traditional state hospital ward returned.

The granddaddy of those programs which maintain persons in the community is that of Fountain House in New York City. Fountain House stresses all those elements of community life that the impaired ex-patient cannot be expected to manage initially. It helps patients with suitable living arrangements, provides social experiences in the form of a club at Fountain House, and has an extensive and successful vocational training and rehabilitation program which returns ex-patients to full participation in the work force. It is highly successful - for instance, it cuts down on return to the hospital by one-half or better.

In addition to these types of programs - there are several with combined hospital and community resources. One of the finest of these is Mendota Mental Health Center in Madison, Wisconsin. This program also stresses the importance of regaining the skills in everyday living necessary to live in the community. It too helps with housing, socialization and vocational rehabilitation. And it too is very successful in enabling persons to live in adequate housing, with dignified employment opportunities, and suitable social contacts.

When we look at the common denominators in programs which were successful in the treatment, care and rehabilitation of the chronically mentally ill, we found several. These programs all had:

- leaders who were dedicated to chronic patients and understood what needed to be accomplished with them;
- aggressive outreach services;
- good monitoring of patients;
- a patient advocacy system (legal and social);
- good interagency referral networks;
- horizontal and vertical administrative structures;
- appreciation of small progress;
- a stable resource base (e.g., financial and community support); and
- good accountability and responsibility systems.

When taken together, one may conclude that there are two elements that are critical to the working of these programs (in addition to teaching the skills in everyday living) that I have not yet stressed: a community support system and case management.

Essentially what I mean by a community support system is a package of resources (housing, income, vocational training, social rehabilitation, psychiatric and other medical care, etc.) that is available and accessible to the chronically mentally ill person. At present, while all such services are available in at least the larger urban areas - they are too few, too far between, and usually not coordinated. So the patient must put together his or her own package, and for person with impaired ego functions - that is impaired ability to get along with people, articulate their desires, know where they are and what they're doing, etc. - this is impossible. So we must, as it were, package these services, and make them available to such disabled persons living in the community - or they will become worse and require hospitalization again, sink into themselves and live out increasingly isolated, reclusive and non-productive lives, or become the annoying bag-ladies and bizarrely dressed crazies talking to themselves and walking stiltingly - sights so familiar to us all.

In addition, in order to link up such persons with this sort of array of services, we require a single person in a unique role. While traditionally, families have served this role, as mentioned earlier, increasingly, discharged patients have no family to return to. So a new role, that of case manager, has been created. This person, assigned a large number of discharged or never-admitted patients, follows them, sees that they receive the services they require, attends to them if they miss connecting with an agency or service, serves as an advocate for the person, and is the glue which holds together the mentally ill person with the services in the community he or she requires, in order first to survive and second to return to full community life.

What then do we need?

We know a great deal now that we didn't know at the beginning of the deinstitutionalization movement 25 years ago. While I will not apologize for the lack of planning, lack of community settings, services and supports; and lack of humane forethought that might have precluded the disasters of the past quarter-century - I am convinced that we have now the scientific basis for intelligent planning for humane services for these individuals.

There is a critical need for more and better housing for the chronically mentally ill; for better vocational training and work opportunities; and for wider application of social rehabilitation principles. In addition we need a reform of the funding that forces patients into the most restrictive setting and discriminates against long-term care; funding for programs which maintain persons in the community and prevent further hospitalization and deterioration as well as for programs which restore patients to higher levels of functioning; alteration of prejudicial community and societal attitudes against the mentally ill; better training for persons who will deal with chronic patients; more research into the causes, prevention and maintenance of chronic mental disease and effective treatments, programs and services systems; resolution of the fragmentation and conflict between and among governmental agencies (HUD, HSA, HRA, etc.) and levels (federal, state, local) involved with funding components of the system needed by such patients; attainment of full civil rights for the chronically ill, and realization that for those chronically mentally ill persons who do not recover any or even partial functioning or who have remissions in their condition, there needs to be both good quality public inpatient facilities and humane asylum settings.

However, these are all outside the scope of this subcommittee at this moment. What concerns me now is the necessity of using what we know today about the importance of:

- Training in the skills of every day living;
- Provision of an integrated community support system; and
- A case management approach

to provide the chronically mentally ill with the best care we know how to provide.

Mr. Chairman, in conclusion let me summarize the state of the art and science as it applies today to the chronically mentally ill patient living in the community. The science of psychiatry, while imperfect, is clear - we know how to treat and care for persons living in the community, given the appropriate resources. The art of delivery of these services is another matter. We have only one Fountain House in New York City, when we need dozens. We have only a handful of community support programs when we need hundreds. And we have only a few dozen case managers, when we need legions.

I thank you for your attention.

SENATOR HATCH

Questions:

1. How to restructure community support programs to better meet local needs?

Community based services are often hopelessly fragmented, if they exist at all. The multiplicity of agencies and authorities typically involved in providing services to the homeless mentally ill need to cooperate and communicate with one another in order to integrate service delivery and avoid duplication. What is needed is a vast expansion of supervised community housing and services and a revamping of the mental health delivery system to meet the needs of the chronically mentally ill. While temporary housing such as shelters may be an important stop gap measure for many of the homeless mentally ill, increasing the numbers of shelters merely postpones the day of reckoning when there will have to be established a provision of comprehensive services, a support system and a system for case management.

2. What kinds of effective approaches could be developed to better serve the chronic mentally ill.

The difficulty associated with providing comprehensive services to this population is that they require an intricate array of medical/psychiatric, social, rehabilitative, and vocational services. This includes services not readily perceived such as assistance in gaining access to their entitlements, opportunities for social intercourse and relief for overburdened families. This is a very heterogeneous and multiple disadvantaged population. Because of this while systems must be interrelated and the services comprehensive the programming needs to be individualized and placed under local (not state) auspices. There is a continuing need for federal involvement through SSI, SSDI, medical assistance programs; there should be a restructuring of those disincentives to work that presently exist in the Social Security Act; and vocational rehabilitation programs need to be better adapted to the chronic patient. There needs to be a partnership between local, state and federal governments.

3. Therapeutic Compliance

Therapeutic compliance may be improved by more sensible commitment laws and procedures, better and more supervised housing, more services available in the community, and closer physician/patient contact.

SENATOR KENNEDY

Questions:

1. Dr. Talbott, what are the most important steps the federal government should take to assure appropriate, cost effective, community-based care for th chronically mentally ill?

Essentially, your three bills contain the important steps the federal government should take to assure appropriate and cost effective community care for the chronically mentally ill, specifically comprehensive programs that contain both medical and psychotherapeutic treatment as well as non-physician psychiatric services (housing vocational rehabilitation, and social rehabilitation). Also needed is supervised housing--graded range and number e.g.--inpatient, day hospitalization, halfway houses, group homes, supervised apartments and case management. There needs to be firstly a provision of services that meet basic survival needs and once those are met, a vast array of comprehensive yet individually determined system of services that provide clinical and rehabilitative support. This population is heterogenous but to one degree or another require the whole list of services as delineated in Section 1919 of S. 1745. There needs to be cooperative efforts by the federal, state and local governments; there needs to be more research into the causes and treatment of both chronic mental illness and homeless; more accurate epidemiological data needs to be gathered and analyzed and, of course more money must be expanded for longer-term solutions for the homeless mentally ill.

2. I recently introduced legislation to establish a system of community-based care for the chronically mentally ill. Would you please give me your overall assessment of this legislation and provide specific suggestions for modifying it so that its enactment would be as helpful as possible to the chronically mentally ill?

While some changes may be indicated insofar as some of the details of your legislation is concerned, on the whole your three bills seems to establish all the services and delivery systems needed by this population. Again I am most pleased by Section 1919 (S. 1745) which would provide the vast array of social, medical and rehabilitative services that are so desperately needed, and particularly of the need for medical mental health services. The changes in Medicare reimbursement (Section 5) are particularly welcome and long over due-this population as well as the Medicare population in general have been sorely neglected by discriminating reimbursement levels for nervous and mental disorders. With the older population rapidly growing and the treatment of psychiatric illnesses increasingly more effective and this is a particularly vulnerable group, it is unconscionable that our elderly most suffer the ravages of mental illnesses without the accessibility of proper and appropriate treatment.

The CHAIRMAN. Dr Williams, it is evident from your testimony that the Davis County Mental Health Center, I think, is a most effective program in meeting some of the broad range of needs of the chronic mentally ill.

Could you describe the ways in which you have been able to obtain funding resources, or sources, to make your program work successfully?

Dr. WILLIAMS. As was mentioned before in the testimony, the partnership is one that is very important, the Federal, State, local partnership, as well as being able to provide and access services through third-party reimbursers.

I think that the concept of having a comprehensive continuum of services available and having an individual responsible or an agency responsible for the coordination of those services becomes more evident as we become more involved.

I think that part of the reason for that is the ability to assume the responsibility of providing a comprehensive continuum of care to individuals experiencing mental illness and working with other agencies and other providers of services and other sources, in order to make sure that appropriate care is given, instead of referring the problem off, or not dealing with it.

I think we are fortunate in our area to have individuals who are interested in working together.

The CHAIRMAN. It has come to my attention that you spend a lot of your time——

Dr. WILLIAMS. I spend a lot of time making sure that that appropriate care is given.

The CHAIRMAN. That is right, but in addition, you spend a lot of time working with the local jails. Could you describe your efforts, especially in educating law enforcement officials on the need for the treatment of these types of individuals who have these problems.

Dr. WILLIAMS. We have found that an ongoing training opportunity for law enforcement officers is necessary. One of the reasons for that is there is a great deal of turnover among law enforcement officers. We have found that by working directly with them on a monthly basis, answering questions that they have and providing training for them to be able to recognize mental illness has avoided a number of these people having to be incarcerated. Oftentimes, the mentally ill exhibit behaviors that are misunderstood, and because of that, they are frightened, in some cases, and law enforcement agents are able to identify these individuals and bring them to us for further diagnosis.

We also go into the jails and work with individuals who are experiencing mental illness who are incarcerated, and make sure that their needs are being met.

The CHAIRMAN. You mentioned in your statement that the Community Support Program needs restructuring in order to be able to better meet local needs. I would like you to maybe take a little more additional time and give us more specifics on that in writing to the Committee, so that we can have some guidance from you—and you also, Dr. Talbott, or any other health professional here. We would like to look at those and see what your total suggestions are.

Also, within the limited resources presently available, I would like you to also write to us and get us information on what kinds of effective approaches could be developed to better serve the chronic mentally ill. We have an opportunity here through this committee that I think can be brought together on this subject, and I intend to do that. We just need as much expert advice as we can so that as we come up with further help for the chronically mentally ill.

Dr. Talbott, I would like to mention that recently, many individuals have expressed their concern to me that there needs to be more Federal research funds devoted to chronic mental illness, including schizophrenia and other serious mental illnesses and disorders.

As the former president of the American Psychiatric Association, could you comment on that?

Dr. TALBOTT. Yes, I could not agree more. The amount of disabling illness that occurs in this country due to the psychotic illnesses in particular schizophrenia and the major affective disorders, and the price of those illnesses, which are either episodic or continual for long periods of time, is enormous to us.

We will only truly deinstitutionalize the remaining patients in the institutions in this country when we do it through research, through effective prevention, effective cure and discovery of the etiology of these illnesses. In my estimation, the underfunding of serious mental illness, which is something like one-hundredth of what it would be for some of the smaller illnesses in the rest of medicine, is something that is an absolute scandal and a tragedy. We are only going to achieve true, good community care when we can address those major illnesses seriously through research.

The CHAIRMAN. In your opinion, how has the prospective payment system helped or affected the care for the chronic mentally ill?

Dr. TALBOTT. Unfortunately, the way it has been implemented so far, Mr. Chairman, has been through lumping large diagnostic groups without taking into account severity and chronicity indices. With this population, those sorts of indices are necessary. In designing a new way of funding for the mental illnesses, we are going to have to take that into account, because we cannot explain with diagnosis alone, more than about 5 percent of the length of stay. So we are going to have to take other things into account, because what we do not want is to see on the one hand, the private and not-for-profit hospitals beginning to close down their doors to the chronic mentally ill, and State hospitals continuing to deinstitutinalize, leaving more people in nursing homes, in jails, or on the streets themselves.

The CHAIRMAN. I might mention that Mrs. Domenici, who is here today, is on the National Institute of Mental Health's Advisory Board. We need to see if we can get them to budge a little bit on that issue, and we will work with you on that That might be the thing to do.

I did not mean to embarrass you——

Mrs. DOMENICI. We will do that tomorrow. [Laughter.]

The CHAIRMAN [continuing]. Let me tell you, when she says she is going to do it, she does it.

Now, is there any data on the cost impact of what you refer to in your testimony on transinstitutionalization? For example, you mention that there are many chronic mentally ill individuals who are currently in prisons. Now, really, doesn't that cost more than hospitalization, or more than even outpatient care?

Dr. TALBOTT. Well, it is hard to cost these sorts of things out. It is estimated, for instance, in New York City, it costs something like $40,000 a year to keep someone in a jail. I think it is inappropriate care.

The CHAIRMAN. It costs much more than the actual dollar cost of keeping them in prison.

Dr. TALBOTT. It is much easier to get a bond issue for a jail than it is for a mental hospital. So that in a funny sort of way, we are using those facilities to shift people, too. If you look at our census in 1950 and 1980, there has not been any change in the total percentage of institutionalized people in this country; it has not gone down. We have only deinstitutionalized one institution—the TB sanitaria. While cutting down State hospitals, we have trebled nursing homes and we have the number of Americans in jails and prisons.

The CHAIRMAN. Well, I would like both of you to write to us with respect to improving therapeutic compliance regarding continuing medication after hospital release or after basic release. If you can give us some ideas on that—it is a touchy problem for us, a difficult problem, and I do not think just asking the generalized question here today is going to be that helpful to us. I think I would like to have your best advice to us and to the committee as soon as you possibly can get it to us.

Is that OK?

Dr. TALBOTT. We would be delighted.

Dr. Williams Yes, sir.

The CHAIRMAN. I want to thank both of you very, very much. Your written statements are wonderful, and your testimony has been excellent, and I am very proud of both of you and glad to have you here today.

Thank you for coming.

I am pleased to welcome our witnesses on the third panel. First, I would like to introduce Dr. Bhasker Dave, who is Superintendent of the Mental Health Institute in Independence, IA. I am grateful for your coming, Dr. Dave.

Second, I would like to introduce Dr. Leonard Stein, who is professor of psychiatry at the University of Wisconsin.

And finally, I would like to introduce to the committee and welcome Joseph Rogers, who is the associate director of the Mental Health Association of Southeast Pennsylvania.

Dr. Dave, we will begin with you. I may have to interrupt you at the end of 5 minutes. Please do not be offended. Just summarize, though, as best you can. Your statements are excellent, and we are going to put them completely in the record as though fully delivered.

Dr. Dave.

STATEMENT OF DR. BHASKER J. DAVE, SUPERINTENDENT, MENTAL HEALTH INSTITUTE, INDEPENDENCE, IA; DR. LEONARD STEIN, PROFESSOR OF PSYCHIATRY, UNIVERSITY OF WISCONSIN MEDICAL SCHOOL, MADISON, WI, AND JOSEPH A. ROGERS, ASSOCIATE DIRECTOR, MENTAL HEALTH ASSOCIATION OF SOUTHEAST PENNSYLVANIA, ON BEHALF OF THE NATIONAL MENTAL HEALTH ASSOCIATION, ALEXANDRIA, VA

Dr. DAVE. Thank you very much, Mr. Chairman.

I too want to thank you very much for inviting me here. I feel that it is a great personal privilege to be here to testify before the Senate Committee on Labor and Human Resources.

My name is Bhasker Dave, and I am the superintendent of the Mental Health Institute at Independence, IA, and am the immediate past president of the Iowa Psychiatric Society. In both these capacities, I have been personally made aware of the concerns and needs of the chronically mentally ill.

In my prepared statement, I have traced the various stages in the pattern of care for the chronically mentally ill. This particular care in Iowa has parallelled the developments across the Nation, namely, creation of the asylums in the 19th century, the mental hygiene movement at the turn of the century, the community mental health center movement, and the deinstitutionalization with rapid emptying of the State psychiatric hospitals.

The chronically mentally ill in the community need a broad range of services, provided by a variety of community based agencies. These services include adequate mental health care, crisis intervention, several psychosocial services, vocational services, appropriate housing and living arrangements, and others.

Often, many of these services are not available within the community or, where they are available, the chronically mentally ill fail to avail themselves of services, drop out of programs, and generally have difficulty negotiating the service system.

To remedy these deficiencies in community mental health care, the National Institute of Mental Health in 1977 launched its pilot Community Support Program, which was designed to stimulate States and communities in developing comprehensive community support systems, or CSS.

The CSS movement has gained a firm foothold in Iowa, being provided currently through 24 of 32 community mental health centers in the State. The first CSS program began in Iowa in 1972. By 1982, 10 centers were providing such services to 18 of 99 counties in Iowa.

Iowa began receiving the Federal CSS funds in August 1982, and the CSS movement gained considerable momentum. By November 1984, 2 years later, there were 24 projects covering 59 of 99 counties in Iowa, with an active caseload of over 1,600 patients.

In Iowa, the major barriers to continued placement and maintenance of the chronically mentally ill in the community include: One, family and public awareness and understanding of the nature of chronic mental illness and resultant behaviors; two, comfort levels of service providers in dealing with persons who are chronically mentally ill; three, sponsorship, resource availability, and interest levels among community mental health professionals in developing and implementing such services where projects are not currently existing; and four, continuation of funding mechanisms for existing community support projects when Federal and State grants expire.

Recently, I saw a 37-year-old patient who was brought to an outpatient setting after he was found living under a freeway overpass in Cedar Rapids. Another 24-year-old man with a documented history of schizophrenia for the previous 5 years was brought to the clinic after he complained of considerable anxiety to his parole officer upon discharge from a correctional facility, where he had been for the previous 15 months. The patient told me:

> While I was in prison, there was a lot of structure, and I could do without my medications Now that I am out, I am feeling extremely tense and anxious, and I feel I had better get back on my medications before I begin to hallucinate again

Patients such as these are indeed being seen by mental health professionals across the State of Iowa. The problems of the chronically mentally ill thus are not unique to the densely-populated or industrialized States, such as New York, Michigan, or California.

The CHAIRMAN. Doctor, let me interrupt you at that point. I think that is a good point to interrrupt you on. There is just no question about it, and we are going to pay particular attention to your full statement. It is an excellent statement, and we appreciate you being here and taking time to be with us today.

Dr. DAVE. Thank you.

[The prepared statement of Dr. Dave follows:]

TESTIMONY

BHASKER J. DAVE, M.D., F.A.P.A.

SUPERINTENDENT
MENTAL HEALTH INSTITUTE
INDEPENDENCE, IOWA

on

THE CHRONICALLY MENTALLY ILL IN IOWA

before the

COMMITTEE OF LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

OCTOBER 9, 1985

Mr. Chairman, and distinguished Members of the Committee

My name is Bhasker Dave, M.D., I am the Superintendent of the Mental Health Institute at Independence, Iowa, one of the four state psychiatric hospitals in the State of Iowa. I am the immediate past-President of the Iowa Psychiatric Society. In both these capacities, I have been personally made aware of the concerns and needs of the chronically mentally ill, barriers in meeting the - needs and priority need areas, in our state. I feel greatly privileged to be invited to testify before the Senate Committee on Labor and Human Resources and present my views on the chronically mentally ill in Iowa.

Background and History

Historically, the pattern of care for the chronically mentally ill in Iowa has paralleled the developments across the nation. In an effort to improve the care of the mentally ill, private and state-supported psychiatric hospitals were opened across the country during the 19th century. The state-supported asylums soon became overcrowded with chronic, indigent patients, and were only able to provide custodial care. The turn of the century saw the birth of the mental hygiene movement with the publication of a book titled "A Mind That Found Itself" in 1908, in which Clifford Beers', a distinguished businessman, described his personal experience as a mental patient. This movement, however, was unable to make any dramatic changes in the care of the mentally ill, and the number of patienta in state mental hospitals increased from 150,000 in 1903 to 512,000 in 1950. These hospitals became increasingly more crowded, the level of care deteriorated, and they became essentially chronic care facilities providing long-term custody of the poor and disabled.

Public and professional concern led ultimately to the formation of the Joint Commission on Mental Illness and Health in 1955 The final report of the Commission, "Action for Mental Health", published in 1961, encouraged the concept of community mental health care The community mental health movement was launched in 1963 with the passage of the Community Mental Health Center Act. Also, in the mid-1950's newer psychotropic medications were introduced and concern was raised about the civil rights of psychiatric patients. These and other factors led to "deinstitutionalization", with rapid emptying of the state psychiatric hospitals. In 1955 there were 559,000 patients in state hospitals in the United States. Today there are approximately 120,000.

In Iowa, four state psychiatric hospitals were constructed during the second half of the 19th century The patient population at these four hospitals decreased from 5,382 in 1954 to 1,074 in 1971 and to 800 in 1984.

A primary objective of the community mental health center movement was to substitute community-based care for frequent or extended psychiatric hospitalization of persons with chronic mental illness. It was assumed that the community mental health centers would provide appropriate aftercare services to continue their rehabilitation in the community and prevent unnecessary rehospitalization. However, evidence accumulated to date suggests that community-based rehabilitation has not been as successful as anticipated

Several factors were recognized as contributing to the difficulty involved in rehabilitating chronically mentally ill people within the community The chronically mentally ill have a host of special and unique problems such as extreme dependency needs, high vulnerability to stress, difficulty coping with the demands of everyday living, deficient interpersonal skills, passivity, tendency towards episodes of acting out behavior, lack of motivation, and lack of adequate social supports. These problems make it difficult for chronically mentally ill individuals to secure adequate income and housing, to develop social support systems, and to hold down jobs in the community. Consequently, these persons need a broad range of services, provided by a variety of community-based agencies. Often many of these services were not available within the community, or where high quality services were available, the chronically mentally ill failed to avail themselves of services, dropped out of programs, and generally had difficulty negotiating the service system. Another deficit in the delivery of community-based services to the chronically mentally ill patient had been the lack of designated responsibility for their care. Different agencies had provided various fragmented services, but no single agency was responsible for coordination of care, continuity of care, and the interagency communication necessary to ensure comprehensive care.

As experience with deinstitutionalization continued, it was recognized that, while major psychiatric disorders could be readily stabilized, they frequently are characterized by indefinite, sometimes permanent, impairment and acute symptomatic flare-ups. In other words, "curing" may be a long-term, possibly lifetime, process.

To remedy these deficiencies in community mental health care, the National Institute of Mental Health (NIMH) launched the pilot Community Support Program (CSP) in the fall of 1977, which was designated to stimulate states and communities in developing "comprehensive community support systems" for mentally disabled adults

In a 1980 NIMH Report "NIMH Definitions and Guiding Principles for Community Support Systems (CSS)", CSS is defined as " .. an organized network of caring and responsible people committed to assisting a vulnerable population meet their needs and develop their potentials without being unnecessarily isolated or excluded from the community"

The ten recognized functions or components of a CSS as stated in the NIMH Report are.

- Outreach. locate patients, reach out to inform them of available services, provide access to needed services and resources by arranging transportation or, if necessary, by taking the services to the patients.
- Basic human needs help patients meet basic human needs for food, clothing, shelter, personal safety, general medical and dental care, and assist them in applying for income, medical, housing and/or other benefits which they may need and are entitled to.
- Adequate mental health care provide ongoing mental health care, including diagnostic evaluation, prescription, periodic review and regulation of psychotropic drugs and community-based psychiatric, psychological and/or counseling and treatment services.
- Crisis intervention provide 24 hour quick response crisis assistance, directed toward enabling both the patient and involved family and friends to cope with emergencies, while maintaining the patient's status as a functioning member of the community. This should include round the clock telephone service, on-call trained personnel and options for either short term or partial hospitalization or temporary supervised community housing arrangements.
- Psychosocial services provide comprehensive psycho-social services

including helping patients evaluate strengths and weaknesses, providing training in daily and community living skills, developing social skills and leisure time activities, and aiding patients in finding and making use of appropriate employment opportunities, vocational rehabilitation services, or other sheltered work environments.

- Housing and living arrangements provide a range of rehabilitative and supportive housing options for persons not in a crisis who need a special living arrangement. The choices should be broad enough to allow an opportunity to live in an atmosphere offering the degree of support necessary while providing incentives and encouragement for patients to assume increasing responsibility for their lives. Some supportive living arrangements must be available on an indefinite duration basis
- Support and assistance: offer backup support, assistance, consultation and education to families, friends, landlords, employers, community agencies and others who come in frequent contact with mentally disabled persons, to maximize benefits and minimize problems associated with the presence of these persons in the community
- Natural support systems recognize natural support systems, such as neighborhood networks, churches, community organizations, commerce and industry, and encourage them to increase opportunities for mentally ill patients to participate in community life
- Grievance procedures establish grievance procedures and mechanisms to protect patient rights, both in and outside of mental health or residential facilities

- Case management facilitate effective use of formal and informal helping systems, by designating a single person or team responsible for helping the patient make informed choices about opportunities and services, assuring timely access to needed assistance, providing opportunities and encouragement for self-help activities, and coordinating all services to meet the patient's goals.

The last function mentioned is perhaps the most significant element of a CSS. A core service agency will have designated responsibility for the continuity and coordination of care of the mentally ill patient via a case manager (single person or team) who is responsible for remaining in touch with the patient no matter how many other agencies become involved Case managers have the responsibility of assessing patient needs, planning to meet these needs with input from the patient and other service providers, linking the patient to other needed service elements, monitoring patient progress, and advocating on behalf of the patient.

Community Support Services in Iowa

The community support services are designed to meet the needs of chronically mentally ill adults Chronic mental illness is operationally defined as adults who have a variety of psychiatric diagnosis, including organic mental disorder; or schizophrenic, paranoid, affective or other psychotic disorder They also 1) have a relatively poor employment history resulting from the behaviors associated with the preceding diagnosis and related episodes of hospitalization; or 2) have the absence or impairment of a functional natural support system such as family or friends; or 3) have a low level of functioning which interfers with the person's abilities to live independently

Current estimates of the number of chronically mentally ill in America range from 1.7 to 3 million. There are an estimated 21,000 adults in Iowa who meet the definition of chronically mentally ill. About one-half of these could benefit from community support services and successfully remain in the community, functioning to their maximum potential.

In November and December, 1982, the Division of Mental Health, Mental Retardation and Developmental Disabilities (of Department of Human Services, State of Iowa) conducted a survey of the ten established CSS projects, which covered 25 counties in Iowa. The survey was intended to provide information on the effectiveness and utilization of CSS by chronically mentally ill patients in the community, to assist in planning for future development of CSS and to comply with federal reporting requirements.

Data was collected on 389 patients, or a sample of 45% of the estimated total of 871 patients participating in these already established CSS projects. Survey findings are summarized below.

Most CSS patients were women, 58% female, 42% male. This is almost the same proportion as in the general CMHC caseload, which is 57% female. Most CSS patients were White (97%), and the remainder Black (2%), Hispanic (.8%) and Asian (.3%). The majority (80%) of CSS patients lived in urban areas. Most CSS patients lived with relatives (37%) or alone (31%). Most CSS patients (80%) had families living within one hour's travel time, and most families (67%) were judged to be supportive.

The majority (53%) of CSS patients were in the 26-44 age group, while 14% were under 25 and 5% were over age 65.

The most common psychiatric diagnosis was Schizophrenia (54%). Affective Disorder ranked second, with 15%, followed by Anxiety Disorder, Personality Disorder, and Adjustment Reaction, each with 5% Most (76%) CSS patients were taking from one to three psychotropic medications, with the largest percentage taking only one psychotropic medication (34%). There were 18% who took no psychotropic medication. The majority of these individuals were taking no non-psychotropic medications (63%), 35% were taking from one to three non-psychotropic medications

The "average" CSS patient was a white female, aged 36, who first had contact for mental health care 10-15 years ago. The average individual had been hospitalized for a total of about 20 months since first contact for mental health care, which was for inpatient services. Since entering CSS, most patients had not been hospitalized. The typical CSS patient had no handicap other than mental illness, had been diagnosed Schizophrenic, and was taking one psychotropic medication.

This "average" patient was a high school graduate, who had never married. Most CSS patients lived with family members in an urban area (defined as 2,500 population or more) About one-third also lived alone. Most were unemployed and not looking for work. CSS families were generally supportive, providing some income The primary source of income for CSS patients, however, was Social Security Disability Insurance. In brief, this "average" patient had met some success; the mental illness was probably well controlled with medication, and patient's family was generally supportive The average CSS patient had not, however, achieved independence at the age of 36, still lived with family, had not married due to poor interpersonal relationships, had not obtained or maintained a job, and, undoubtedly, was straining family resources.

The most heavily used component services were mental health care (97%), case management (96%), psycho-social services (90%), outreach (90%), and support and assistance to families/communities (87%). The emphasis in CSS in Iowa, therefore, seems to be in locating CSS patients, linking them with mental health services, facilitating the patient's use of the formal and informal helping networks, and in offering support to families and communities to ease the patient's adjustment to the community environment.

Over half, used the components of meeting basic human needs (68%) and crisis intervention (66%). This finding may reflect the patient's relative success in obtaining family support or entitlements through other agencies such as the State Department of Human Services. Data on current income indicated that 62% received some type of Social Security entitlement An almost equal number were wage earners (12%) or received monetary support from relatives (12%) as their first source of income. The fairly high usage of crisis intervention services speaks to the need for quick response to alleviate stress, which may precipitate hospitalization.

The most infrequently used component services were housing and living arrangements and grievance procedures.

Issues and Barriers

Community support services are effective if, in addition to the designated case manager function, adequate support, skill building, and treatment services are available. The current situation in Iowa indicates that while almost half the state has case management and social adjustment service components available, specialized living arrangements (supervised apartments), partial hospitalization (day programming), and vocational services (particularly on-the-job training) are not available.

The major barriers to continued placement and maintenance of the chronically mentally ill patient in the community include:

- Family and public awareness and understanding of the nature of chronic mental illness and the resulting behaviors which can be expected of persons with this illness;
- Comfort levels of providers of services and other non-providers (i.e., landlords) in providing services and dealing with persons who are chronically mentally ill,
- Sponsorship, resource availability, and interest levels among community mental health professionals in the development and implementation of community support services where such projects currently do not exist and
- Continuation of funding mechanisms for existing community support projects when federal and state grants expire.

Priority Need Areas

The following priorities for continued community support project development and enhancement were developed in coordination with the Statewide Community Support Planning Committee and the Case Managers Group of local community support projects. They are based upon the needs assessment survey as well as available data from the various individuals and organizations involved in delivering services to chronically mentally ill patients.

- Development of case management projects in those community mental health center service areas that do not have community support services projects at present,

- Expansion of existing community support services components other than case management in areas of the state that do not currently have such components, particularly socialization and drop-in centers, day programming supervised apartment, and other living arrangements;
- Availability of emergency services with face-to-face back-up in rural communities when a chronically mentally ill patient has a crisis; and
- Availability of continued training and technical assistance to local community support services providers in such areas as clinical skills building, developing and using volunteers, constituency building, and developing family support groups.

Current Status of CSS in Iowa

CSS has gained a firm foothold in Iowa The case management component of community support services is provided through 24 of 32 community mental health centers in the State

While the first CSS program in Iowa began in 1972, the development of comprehensive CSS programs as defined by NIMH began in 1979. By 1982, ten centers were providing community support services to 18 Iowa counties.

These CSS programs served 871 individuals in FY'82. A total of about $612,000 was spent on CSS programs in Iowa in FY'82. The average program cost was approximately $61,000, averaging about $700 per CSS patient per year.

Iowa began receiving federal CSS funds in August, 1982. This led to considerable growth in CSS, and by November, 1984, there were 24 projects covering 53 counties in Iowa with an active caseload of about 1,632 patients. Additionally, a number of persons were receiving partial hospitalization (269 patients) and vocational services (806). (Some patients may even be receiving all three services. The count is not unduplicated.)

The 1982 Iowa survey indicated that CSS participation resulted in a reduction in length of time spent in inpatient care. Prior to CSS, 69% of the patients had been hospitalized more than three months; since CSS only 12% had been hospitalized a comparable length of time. Prior to CSS, 35% of the patients had spent more than a year in a hospital. Since CSS, only 1% have spent more than a year in hospital care. Average number of days spent in the hospital was reduced from 62 days pre-CSS to 22 days post-CSS.

Just last week I saw a 37-year old man who was brought to an out-patient setting after he was found living under a freeway overpass in Cedar Rapids. Another 24-year old man with a documented history of Schizophrenia for previous five years was brought to the clinic after he complained of considerable anxiety to his parole officer, upon discharge from a correctional facility where he had been for the previous 15 months. The patient told me, "While I was in the prison there was a lot of structure and I could do without my medications. Now that I am out, I am feeling extremely tense and anxious and I feel I should get back on my medications before I begin to hallucinate again."

Patients such as these are indeed being seen by mental health professionals across the State of Iowa. The problems of the chronically mentally ill, thus, are not unique to the densely populated or industrialized states such as New York, Michigan or California, but indeed are a nationwide concern. With the crisis in farm economy, residents of rural states like Iowa, are facing painfully challenging times, particularly those who must turn to the State and Federal governments for assistance in coping with financial, emotional, health or social dilemmas. Faced with limited revenues, extremely tight budgets and high caseloads, the providers of care for the chronically mentally ill, must come up with innovative approaches to service delivery and the ability to maintain these services at the highest possible levels.

I believe that a properly planned and developed Community Support Services System can indeed provide appropriate and adequate care to the chronically mentally ill in the local community, and reduce considerably the need for repeated hospitalizations for many of them

Mr. Chairman, I want to thank you and the Committee for your attention

The CHAIRMAN. Dr. Stein, let me turn to you at this point.

Dr. STEIN. Thank you, Mr. Chairman.

I am Leonard Stein, professor of psychiatry, University of Wisconsin Medical School, and medical director of the Dane County Mental Health Center.

Our mental health center has been designated by the National Institute of Mental Health as a national training resource for community support programs, and over the past 2 years we have trained over 250 people from 30 States and several foreign countries.

I would like to make several points today. One is to make a comment on the deinstitutionalization debate; talk about the clinical problems chronic patients have, and give an example of a successful system of care.

The CHAIRMAN. Doctor, could I interrupt you for a second?

Dr. STEIN. Certainly.

The CHAIRMAN. I have to leave, and Senator Grassley has been kind enough to come, not only because of Dr. Dave being here, but to chair the rest of the hearing.

This hearing is particularly important to me and other members of this committee. We have really appreciated the efforts that have been put forth. And I want all of you to send in the information that I have been asking for throughout this hearing, in addition to the excellent statements you have given us here today.

I want to thank my colleague for being willing to chair the latter part of this hearing so that I can get to another very important appointment. This is, I think, one of the most important hearings we have held in a long time, and certainly, in this area.

Senator GRASSLEY [presiding]. I would ask you to continue in the same order and under the same conditions as the chairman previously announced.

Dr. STEIN. Certainly.

The three areas that I want to touch on today are the deinstitutionalization debate; the clinical problems of chronic psychiatric patients, and give an example of a successful system of care.

First, on the deinstitutionalization debate, the deinstitutionalization movement is conceptualized as a two-step process—outplacement of patients from public mental hospitals into the community, and second, the coincident development of community-based systems of care.

When we read about the homeless mentally ill, the mentally ill in jails, the mentally ill who are revolving in and out of our hospitals, we have read that deinstitutionalization has been a failure. However, when one looks at areas where comprehensive systems of community-based care have been put into place, in every instance, it has been a success. Thus, the failure has not been deinstitutionalization, but the failure to complete the deinstitutionalization movement by the development of comprehensive systems of care.

Because of time, let me skip on and talk about a successful system of care that was developed in Dane County, WI. Dane County has a population of 330,000 people. Because two of the Wisconsin State hospitals are in our county, and many patients from other counties were discharged into Dane County, we are overrepresented with chronic mentally ill people. Nevertheless, we have developed a very successful system of care. We have case management, assertive outreach, which ensures that people who drop out of service or who do not want to come in for services get services by our staff going to their homes, neighborhoods, places of work, on the streets, et cetera. We have crisis intervention services available 24 hours a day.

As a result of that, hospitalization in Dane County is very low The revolving door syndrome has been virtually eliminated. There are virtually no homeless mentally ill in Dane County. We have not transinstitutionalized our population; that is, we have very few in jails, we have no large nursing homes. The vast majority of our people are living in independent settings.

In other words, deinstitutionalization has been a success in Dane County.

It is important to note that Dane County is not richly funded with mental health funds. In fact, we get less than the national average per capita for mental health funds. The way we have been able to develop this comprehensive system of community-based care is by reallocating funds. In other words, the national average is to spend 70 percent of the mental health dollar on the hospital, 30 percent in the community. In Dane County, we spend only 15 percent on hospital care, 85 percent on community care.

This ability to reallocate funds has made it possible for us to develop a comprehensive system of care which has shown that deinstitutionalization can be successful.

There are many barriers to these kinds of programs to be spread throughout the country, and those barriers were mentioned earlier by earlier witnesses. Let me just say that the proposed legislation has potential to make a significant impact on some of these barriers.

Thank you very much.

[The prepared statement of Dr. Stein follows:]

STATEMENT OF LEONARD I. STEIN, M.D.

Mr. Chairman, my name is Leonard I. Stein. I am a psychiatrist and professor of psychiatry at the University of Wisconsin Medical School. I will summarize my testimony and, with the committee's permission, submit the full text for the record.

My special concern is the treatment of chronic psychiatric patients and I am a member of the American Psychiatric Association's committee on the chronic mental patient. In the early 1970's I was the co-developer of a program for the treatment of chronic psychiatric patients that won the American Psychiatric Association's Gold Medal Award in 1974. I am Medical Director of the Dane County Mental Health Center in Madison, Wisconsin, which has been designated by the National Institute of Mental Health as the National Training Resource for Community Support Programs for the chronically mentally ill (CMI). In the past 24 months, we have trained more than 250 persons from 30 states and several foreign countries.

Today I will outline the principles of treatment, describe a system of care based on those principles, and finally outline the barriers which have interfered with the development of needed services for CMI persons. Before going on to those three areas, I would like to clarify the debate about deinstitutionalization.

We have read about the homeless mentally ill, about the mentally ill being put into jail instead of being treated and about mentally ill rotating in and out of our hospitals. We are told that these are the consequences of deinstitutionalization and thus deinstitutionalization has failed. To understand what went wrong, we must remember that deinstitutionalization was conceived as a two-step process: 1) outplacement of patients from large public mental hospitals and 2) the coincident development of a comprehensive system of community-based services for those patients. We know the first step was enormously successful. We have reduced public mental hospital populations from more than 550,000 in 1955 to less than 150,000 today. Unfortunately, in most parts of the nation, the second step has not yet been taken.

The consequences of failure to develop community based systems of mental health care for chronic mentally ill people are described above and thus we have substituted one poor system of care, the "warehousing" of patients in large state institutions, for another system that is equally inadequate and inhumane, -- neglect, transinstitutionalization and the "revolving door" syndrome, allowing patients in our communities to deteriorate, hospitalizing them, then once more discharging them to inadequate care, only to deteriorate again and return to the hospital again and again.

However, the knowledge we have accumulated in the past 15 years supports the premise that we can outplace patients from our hospitals and provide them suitable care in the community. We have learned how to help chronic psychiatric patients live a stable life in the community. <u>In every instance where a comprehensive system of community care for the chronic mentally ill has been established and evaluated, it has been successful. Thus, deinstitutionalization has not failed, the failure has been to complete the deinstitutionalization process through the development of comprehensive systems of community care for CMI persons.</u>

The Clinical Problem - Conceptual Framework

To understand the kind of treatment the CMI person requires, it is important to understand the illness they suffer from. These persons suffer from a chronic illness whose onset is usually in late adolescence or early adulthood, and which is lifelong in duration. To date we neither know how to cure or prevent the illness. But over the past 15 years we have learned a great deal in how to improve its management. It is an illness characterized by exacerbations and remissions - i.e., there are periods when it worsens and periods when it is more quiescent. During a flareup the patient suffers an impairment in his ability to test reality. The patient may hear voices, believe he is being persecuted and behave in bizarre ways. We know how to quickly and effectively to treat the flareup through the use of medications and at times the appropriate use of the hospital. During the quiescent period the patient is generally in good touch with reality but suffers from other impairments which interfere with his ability to make an *unassisted* stable adjustment to community life. Those impairments are the following: Sensitivity to stress, difficulty with interpersonal relationships, and a deficit in coping skills. The therapeutic strategy is to prolong the stable or quiescent stage as long as possible and decrease the frequency, intensity and length of time that the flareup stage occupies. This therapeutic strategy is no different than that used with people suffering from other chronic illnesses such as arthritis or diabetes, which are also illness characterized by exacerbations and remissions, have no prevention or cure, and where we have learned quite well how to manage the illness so as to prolong the periods of relative quiescence and increase the patient's ability to function in the community.

The major clinical problem presented by persons suffering from CMI is helping them organize and maintain those needs that are necessary to establish a stable adjustment to community life. The needs are quite obvious; in essence they need exactly what the rest of us do. They need a place to live; they need an opportunity to socialize; they need some kind of meaningful vocational or avocational activity that anchors their day, gives them a reason to get up in the morning, and gives some meaning to their lives; they need finances; medical services; mental health services and crisis intervention services. Their only need that the rest of us do not specifically require is support directed at the community in which they live. The community must be helped to learn how to accept their presence and accept them as members. Any treatment organization that works with this population must understand that supporting the community is just as important as providing support to patients. The reason the CMI person has difficulty in arranging and maintaining the above needs is a consequence of their impairments of sensitivity to stress, difficulty with interpersonal relationships and deficit in coping skills. These impairments are ongoing, do not respond to medication and must be addressed on an ongoing basis. Research has clearly shown that hospital treatment does little to influence these impairments and that community treatment does have a significant impact on helping patients maintain a stable adjustment to community life. In summary, effective treatment of CMI must have a comprehensive and integrated system of community based services as the primary locus of care. Services must not be time limited; CMI persons suffer from a life-long disorder and thus treatment must be ongoing in nature.

The following section describes the principles we have found effective in working with the patient and working with the community.

Working with the Patient

I. An assertive approach to monitor patients, seek them out if they do not come in for services and actively work to keep them involved in treatment.

II. Tailor treatment to meet the individual needs of patients. Interpret treatment broadly so that it includes everything from medication to financial assistance.

III. Provide in vivo services so that when necessary staff will go and work with patients in their homes, places of work, the streets, etc.

IV. Capitalize on patients' strengths. In addition to treating psychopathology, recognize patients' strengths and utilize them in the habilitation process.

V. Provide sufficient support to patients to keep them motivated to continue the hard work of adjusting to life in the community. The amount of support will vary and thus must be titrated so as not to retard the growth towards autonomy.

VI. Relating to patients as responsible citizens. In order to increase patients' autonomy and decrease community resistance to CMI persons living in the community, it is crucial that both patients and other community members recognize that CMI persons are full fledged citizens of the community and thus have both a right to be there and an obligation to be law abiding members of the community.

VII. Crisis services must be available 24 hours a day, seven days a week. These services must truly help persons resolve their crisis rather than acting as a conduit to the hospital.

Working with the Community

Providing support to the community members who are in contact with our patients such as family members, landlords, storekeepers, agencies and so on is just as important as working with the patient himself. These community members' attitudes about and modes of relating to patients are significant factors in influencing how well our patients do. The following are the principles we use in working with the community.

I. An assertive approach is as crucial to successfully working with the community as it is to working with patients.

II. Utilizing a wide variety of community resources. There are many services available to the citizens of the community that were not specifically created to help CMI persons. With education and support many of these services can be made available to the CMI citizens of the community.

III. Providing education and support to community members. Educating shopkeepers, landlords, police, etc., in how to relate to CMI persons and giving them support when needed leads to better patient functioning and greater community acceptance of CMI persons.

IV. Retaining responsibility for patient care leads to ensuring continuity of care. Although many providers of service, from private physicians to social welfare agencies, are involved with a CMI person; the responsibility for ensuring that the services are actually delivered in an integrated fashion must be fixed to one agency or case manager.

V. Working with the family is crucial to a successful outcome. For too long mental health professionals have victimized families of CMI persons by holding them responsible for causing the illness. We now know better and have learned useful ways of helping families and their ill member.

An Example of Comprehensive Community Services for the CMI

Dane County, Wisconsin, has a population of approximately 300,000 persons. Approximately 175,000 live in Madison with the remainder living in small towns and farms. Dane County has a nationally recognized comprehensive community support system for chronic psychiatric patients. The county has identified approximately 1100 individuals suffering from chronic mental illness and has creatively used funding mechanisms to develop a broad-based, multi-agency system of care for its CMI population. It is important to note that the system is <u>not</u> especially well-endowed with funds to run a "model" program. In fact, Dane County receives less than the average Wisconsin county per capita for its mental health programming. There are primarily two factors which have made it possible for this county to provide excellent services to the CMI. First, it is the county's policy that its highest priority is to treat those in greatest need of treatment; i.e., persons suffering from severe mental illness and those in crisis. Secondly, it uses what funds it does have creatively to develop incentives for the service providers to treat this population in the least restrictive alternative. The major strategies to accomplish the above are budget strategies and comprehensive community programming.

Budget Strategy

Limited resources cannot support both a large hospital population and a comprehensive system of community based programs. Fortunately, the availability of comprehensive community services dramatically reduces the need to use the hospital and produces a superior long-term clinical result. In order to promote community based services, Dane County contracts with a wide range of community based providers for services with an emphasis on services for the CMI [illegible] and persons in crisis. In addition, Dane County budgets for anticipated inpatient costs based on last year's usage. If actual inpatient costs are coming in lower than projected, unused monies are funneled to existing agencies to increase community based services. On the other hand, if inpatient costs exceed the budgeted amount, community program budgets for the following year are cut in order to budget for the anticipated higher inpatient costs. This is all possible because the dollar literally follows the patient. If patients are hospitalized in any hospital including the state hospital, the county pays the bill. Contracting for services also makes the above procedure possible since the service providers are, for the most part, non-profit corporation agencies not county agencies, and thus are not protected by civil service. The jobs of the staffs of those agencies are literally dependent on there being sufficient money in the county's mental health budget to support their salaries. If the inpatient bill goes up everyone is acutely aware that agency budgets will be cut and jobs will be lost. This fact provides real incentives to work with difficult patients rather than get them out of the system through long-term hospitalization. Short-term hospitalization is used when necessary and since the need to use the hospital varies inversely with the comprehensiveness of community programming, the system for community care becomes self-reinforcing.

The county uses two monitoring mechanisms to keep hospital costs down. The first is to use the Crisis Intervention Service (CIS - which will be described in the next section) to act as gatekeeper of all patients on county monies who are admitted to the hospital. The county has given CIS the power to authorize or withhold payment to hospitals and attending physicians for inpatient care. The CIS screens all patients presenting for admission and either authorizes payment for inpatient care or takes over the clinical responsibility for treating the person in the community. Over the past five years they have averted approximately 75 percent of the potential admissions. The other monitoring mechanism is to monitor treatment when a patient is admitted. Every county funded hospitalized patient is assigned to a community based service to monitor their treatment while in the hospital. These patients are thus continued to be followed by the community program while in the hospital. The monitoring agency works closely with the inpatient staff in treatment of the patient and discharge planning. This ensures that length of stay be no longer than necessary.

These mechanisms of incentives, gatekeeper, and monitoring help keep hospital use at an appropriate level and thus ensures there will be sufficient funds for comprehensive community based treatment.

Comprehensive Community Services

As noted earlier, Dane County's mental health services are broad in scope and are provided for by a number of different agencies. The following are brief descriptions of some of the programs to give the reader a sample of what is available.

Crisis Intervention Services

The Dane County Mental Health Center provides 24 hour per day; 7 days per week crisis intervention through a mobile team which is available to immediately assist persons in crisis by going to where they are. In addition to this mobile team, the Center mans a 24 hour per day telephone service which screens calls, and those which require the mobile service are transferred for their immediate attention. Both the mobile team and the telephone team are trained personnel who are available at all times. The crisis team is authorized by the county to act as gatekeeper of all county paid for hospital services.

Mobile Community Treatment Team

This service is a direct replication of the Training in Community Living Program which won the American Psychiatric Association's gold medal award in 1974 as an alternative to mental hospital treatment. It is a unit that specializes in working with the difficult to treat CMI. The majority of their patients are young adult persons with chronic schizophrenia who are for the most part unwilling to come in for services and must be outreached . Programming is individually tailored to each patient and consists of teaching patients daily living skills and working with them and community members and agencies to help the patient develop and maintain a support system. Being involved in some kind of work activity is an important aspect of the program and much is done with sheltered workshops, employers, and voluntary job placements with charitable organizations. The program operates two shifts a day, seven days a week with CIS covering the midnight shift.

Support Network - A Day Treatment Program

The support network program is the Dane County Mental Health Center's psychosocial rehabilitation unit for chronically mentally ill adults. The program has adopted many of the principles utilized by Fountainhouse. The program operates on a continuous routine basis for a scheduled portion of a 24 hour day and is dedicated to providing effective and comprehensive services to assist the CMI in leading a more independent, healthy, successful and fulfilling life in the community. The program works with the patients who generally are more stabilized than those patients served by the Mobile Community

Treatment Team. Nevertheless, this program provides case management services for its clients as well as outreach services.

Vocational Services

Dane County provides a wide variety of opportunities for vocational services. Dane County has two sheltered workshops in which approximately one-third to one-half of the client population of each are chronically mentally ill persons. In addition to these sheltered workshops there are several other resources that do provide work training and opportunities for [illegible] chronically mentallv ill person.

Living Arrangements

The vast majority of the 1100 chronic mentally ill living in Dane County are living in independent settings. There are, however, approximately 450 who are receiving specialized help with their living arrangements in a continuum from high structure to low structure. Most of these 450 persons live in apartments which are regularly visited by persons working in our Special Living Arrangements program.

Inpatient System

Hospitalization is one important element in a comprehensive community support system. Crucial, however, is that the primary locus of care remains in the community even though the patient may be in a hospital for a short period of time. Dane County has for its use the psychiatric units of four general hospitals, a unit in a county hospital, and the state hospital. As noted earlier, CIS acts as the gatekeeper for admission to all those units and each hospitalized patient is monitored closely by a specific community service assigned the case. In addition, a weekly list of inpatients is provided key members of the system who monitor their lengths of stay very closely. As a result of these practices, patients in the hospital are not forgotten and hospital stays are relatively short.

The above description of programs is a brief encapsulation of a very comprehensive system of care, only a small number of the programs that make up that system were described.

Conclusion

Dane County, Wisconsin, has developed a comprehensive system of community based programs for its citizens needing mental health services. There is a heavy emphasis in its programming for people in crisis and for persons suffering from severe and/or chronic mental illness. Programs for the CMI person are not time limited and their goals are maintenance of stability and improving the quality of life rather than cure. Results have been highly gratifying. As noted earlier, of the 1100 identified CMI persons in the county, 75 percent live in independent settings, few of which are of low quality. Case management is assertive and few people get lost to the system. A range of community programs are available to meet the needs of the population. As a result, hospitalization rates in Dane County have been dropping for the past few years, whereas for the United States as a whole, hospital admissions have been increasing. In addition, length of stay is short and readmission rates are approximately 25 percent, which is less than half the national average. The low readmission rate is even more striking when one considers that in this system only the most severely ill get hospitalized.

This system of care, that is truly responsive to those in greatest need in our community, could not have been developed if the mechanisms for controlling inpatient costs were not available. In the United States, on the average, 70 percent of the mental health dollars go to support hospital services, leaving only 30 percent for community services where the vast majority of the patients reside. In Dane County, on the other hand, 15 percent of the mental health dollars goes for inpatient care while 85 percent supports community based services. From our experience, one could argue that nationally there is sufficient money already in the system to provide good care if only that money was more rationally distributed. To accomplish this requires both a clinical policy to provide community based services and a fiscal policy that provides real incentives to treat in the community.

Barriers to Developing Services for Chronic Mentally Ill Persons

As I mentioned earlier, the deinstitutionalization process was not completed. Although over 400,000 persons were outplaced from public mental hospitals, adequate community based services for those persons were left largely undeveloped. To complete the process of deinstitutionalization, a comprehensive and integrated system of community based care needs to be put into place. However there are are a number of barriers which interfere with the development of that system. These barriers include a lack of sufficient trained professionals working in this area. A paucity of a relevant curriculum in our professional schools of social work, psychiatry, psychiatric nursing, and psychology. In addition, there is a virtual absence of role models among the faculty in our training institutions who are doing this kind of work. Other barriers are the resistance of unions to shift the site of work from hospitals to community and the resistance of communities to tolerate idiosyncratic non-lawbreaking behavior among chronic mentally ill persons. Also, there are few fiscal incentives to induce states and local communities to develop community based systems of care as alternatives to hospital treatment and SSI and Medicaid regulations which do not facilitate and at times hamper chronic mentally ill persons from making a stable adjustment to community life.

As I understand the proposed legislation, it does much to overcome these latter barriers. As noted, currently there is not a strong federal fiscal incentive for states to change their primary locus of care from hospital to the community. This legislation will ask each state to plan for community based services in order to be eligible for public health service funds. This plan must include case management for every chronic mentally ill person, to help ensure that services are integrated and that there is continuity of care. It will induce states to look at their mental health services as a system rather than as fragmented pieces. In addition, it will require states to include community services in their Medicaid payments. Further, the proposed legislation will address another barrier that interferes with chronic mentally ill persons from making a stable adjustment to community life - difficult in gaining SSI support and, once gained, losing SSI support to maintain a dwelling if hospitalized even for a short period of time. The proposed legislation will help the disabled chronic mentally ill person gain SSI support if they are discharged from an institution, are in imminent risk of being institutionalized, or if they are homeless and willing to become involved in services. In addition, if the chronic mentally ill person is hospitalized for a temporary stay, the SSI will maintain his dwelling and thus greatly facilitate his moving back into and staying in the community. These changes in the SSI regulations will make a significant difference in helping chronic mentally ill persons live in the community. Another problem faced by mentally ill persons is the loss of their Medicaid eligibility and, thus, often the loss of needed medical services if they become gainfully employed. The proposed legislation will continue Medicaid for three years after the loss of SSI, which will not only help in gaining needed medical care for these persons, but removes one of the disincentives towards becoming gainfully employed.

We know how to help CMI persons live stable lives in the community. We have successful programs operating in many areas of the country. There are, however, significant barriers to having these programs become widespread. As a result great numbers of CMI persons suffer from neglect and inappropriate treatment. Much needs to be done to help remove these barriers - the proposed legislation is a significant step in that direction.

Senator GRASSLEY. Mr. Rogers, would you take your 5 minutes now?

Mr. ROGERS. Sure, Senator. Thank you for having us here.

I am humbled by the presence of the folks on the panels that have preceded. I am a former mental patient myself. I was diagnosed as paranoid schizophrenic. I look at the charts, and I am humbled by the fact that on a panel of this size, and the presentations, and the numbers of people who have presented here, that I have the position of trying to represent 1 of those 6.4 million episodes, if not people.

My own experience with the mental health system has been a rocky one. I was hospitalized in both public and private hospitals. On coming out of the hospital, I found that there was really a total lack of information and availability of the knowledge I needed to be successful in the community.

I was not able to work. I came from a family of 12 generations of Americans who have farmed this country and have built factories and built dairies, and worked in this country to make it what it is today. My uncle died in World War II. But I was not able to participate as a full American because of an illness, because I was struck down at the age of 19 by something that I could not explain and very few people could explain to me.

I did not understand that there were supports for me at the time; in fact, I had been given misinformation by a counselor. I did not know that there was welfare and food stamps and possibly, Social Security for me. That left me with very little options, because my father had died when I was 16, and my mother was a chronic alcoholic and was not available to me.

The situation I faced was one of ending up homeless and on the streets of Atlanta, GA. I had no money, I had no contacts. Because of my behavior, I feel—and I now take responsibility for some of that behavior, but also because of some illnesses—I had very few friends and people that I could relate to.

Luckily, there was developing in Florida at that time, where I was growing up and had these incidents, a program of community support, a halfway house that was opened with the help of the Seventh Day Adventist Church. A couple took me in and cared for me for over a year and a half. Basically, that saved my life.

I was happy to be able to shake the hand of Senator Kennedy earlier, and that the community mental health center that was established under the act, and the efforts and work of his brother, was a place where I could go and meet with somebody who could begin to try and explain some of the things I was finding and what was happening to me.

But still, there was very little in terms of jobs or job training. I tried to go to college, but the college was not the kind of experience for somebody who was suffering on a day-to-day basis with hallucinations and fears and anxieties. There was no job training, and to this day, there is really not much in the way of job training.

We are individuals who have a disability, who have a handicap, but we want to work, we want to participate as full citizens. We do not want to be on the welfare rolls. What do we need to get off the welfare rolls? What do we need to get off the Social Security? We need incentives to be able to do that.

If you are making $500 or $600 at the maximum on Social Security, it is very risky to try and get a job and work when you know your illness is a cyclical illness. It took me over 10 years before I fully recovered, with periods of being able to participate in society and do some minimal work, but other periods where months of my life would be lost to hallucinations and incidents that it would take me much more than the 5 minutes here to begin to even explain.

So, we need the supports; we need to be able to have the incentives, but we need to be able to have supports to do that. We need the help of advocates for us in the community who can speak and work with us so we can speak for ourselves.

Thank you very much, Senator.

[The prepared statement of Mr. Rogers follows:]

National Mental Health Association
1021 Prince Street • Alexandria, Virginia 22314-2932 • (703) 684-7722

STATEMENT CONCERNING

ACCESS TO MENTAL HEALTH SERVICES

BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

BY

JOSEPH A. ROGERS

Associate Director
Mental Health Association in Southeastern Pennsylvania
Philadelphia, Pennsylvania

On Behalf of the

NATIONAL MENTAL HEALTH ASSOCIATION

Wednesday, October 9, 1985

Mr. Chairman,

My name is JOSEPH A. ROGERS. I am the Associate Director of the Mental Health Association of Southeastern Pennsylvania in Philadelphia. As a former mental patient, I have experienced many aspects of the public and private mental health service delivery systems, both in my native state of Florida and in New Jersey where my wife and I currently live.

I was first diagnosed with a mental illness at the age of 12, and have struggled with the effects of mental illness since then. I am 33 years old. In addition to periods of hospitalization, I have been a client of the vocational rehabilitation system, a resident of a half-way house in New Jersey, and have had periods of homelessness and joblessness. Since 1980 I have organized consumer self-help and advocacy groups, first in New Jersey where I was the director of a statewide project of the New Jersey Self-Help Clearinghouse, and later in Philadelphia where I founded Project SHARE (Self-Help and Advocacy Resource Exchange) for the Mental Health Association of Southeastern Pennsylvania. I consult nationwide on the development of consumer self-help and advocacy groups, and am a member and Interim Coordinator of the recently organized National Consumers Conference Steering Committee, a nationwide network of consumer self-help and advocacy groups.

I testify today on behalf of the National Mental Health Association. In my oral testimony I will illustrate from my personal experiences problems in accessing appropriate mental health services and community support systems. This written testimony will provide greater detail on the problems of access, will describe the work and recommendations of the coalition of national mental health organizations on mentally ill persons who are homeless chaired by NMHA, and will comment on bills by Senator Edward M. Kennedy which NMHA has reviewed in draft form concerning services for chronically mentally ill persons. I would like to bring particular attention to the appendix of letters from persons struggling with the effects of a mental illness, either personally, as a family member, or as a care giver.

The NATIONAL MENTAL HEALTH ASSOCIATION (NMHA) is the nation's oldest and largest non-governmental, citizens' voluntary organization concerned with mental illness and mental health. Founded in 1909 by Clifford Beers, who suffered from a serious mental illness, the Association has historically led efforts on behalf of mentally ill people in institutions and the community.

The NMHA has grown into a network of 650 local chapters and state divisions working across the United States. It is composed of volunteers who are mostly non-mental health professionals. Some are family members whose loved ones have been affected by mental illness; others are former patients. All are committed to advocacy for the improved care and treatment of mentally ill people, the promotion of mental health and the prevention of mental illnesses.

Access to America's Mental Health Service System

For 76 years, the Mental Health Association has lead efforts to develop a comprehensive, coordinated system of community-based mental health and support services with continuity of care in every area of the country. Regretfully, Mr. Chariman, the Association must report that the nation is falling behind in the great advances made toward these goals over the past several decades. Although states have made significant improvements in their mental health service systems, much more needs to be done. Additionally, the federal government has failed to follow through on its commitment to quality care for mentally ill persons. This undermines efforts of state and local governments and the private sector to improve the care and lives of mentally ill persons.(1)

Traditionally, services for mentally ill persons, especially those generally described as chronically mentally ill, have been provided by the public sector, with states exercising much of the responsibility. Federally, several programs are essential to providing basic income support and health care for mentally ill individuals, while others are crucial to state and local efforts to plan for and meet the full range(2) of treatment and support services needed.

The deinstitutionalization and community mental health policies of federal and state govenments have effected a radical refocusing of the patterns of mental health care. The related goals of preventing unnecessary admission to and retention in psychiatric hospitals, and providing treatment and care in communities are beginning to be met. Under federal leadership, state and local efforts have caused the development of nearly 800 comprehensive community mental health centers and thousands of other outpatient, residential, psychosocial rehabilitation, partial hospitalization, and other community support programs.(3)

State hospitals census are dramatically reduced (138,00 patients in 1980, a 75 percent drop from 559,00 in 1955)(4), reflecting a redefined use of these facilities from primarily long-term care facilities, to multiple-service facilities providing forensic services, preventive detention for mentally ill people who are considered dangerous to others, protection of those who are at risk of harming themselves because of their mental illness, long-term care for certain people who are chronically disabled, and the "mental health safety net" caused by the lack of sufficient, appropriate community-based programs.(5) According to the National Association of State Mental Health Program Directors most state mental hospitals today have a rapid turnover of acute patients(6) (the majority of admissions are for less than a month)(7).

It is now recognized that most people with a mental illness, including those perceived as being severely ill and disabled, can live in their home communities even during acute episodes of illness, provided they have access to a range of life support, health, and mental health treatment and rehabilitation services. A 1983 joint study by the Department of Health and Human Services and the Department of Housing and Urban Development concluded that "Over the past two decades, it has been convincingly demonstrated that people with chronic mental illness can become more productive members of society if they have appropriate community living arrangements linked to rehabilitation and support services."(8)

Few such arrangements exist, however, for the estimated 1.7 to 2.4 million people(9) living in institutional and community settings who, by virtue of their diagnosis, duration of illness and resultant disability, may be termed chronically mentally ill. While many of these people live successfully in their communities, many others are inappropriately placed in institutions such as public mental hospitals and nursing homes, many live in substandard or inappropriate housing and many are homeless.

Thousands of people currently in hospitals or nursing homes could function more independently in psychosocial programs, group homes, family foster care or supportive apartments if adequate numbers of such programs were available. For example, a study sponsored by the Commonwealth of Massachusetts Department of Mental Health showed that between 50 and 75 percent of the admissions to the State's mental hospitals could be avoided if adequate community services were available. Another study in New York State documented that 9,000 of the 21,000 inpatients in the state psychiatric centers (hospitals) would be better served in the community;(10) and a series of assessments of the state hospital populations in seven states concluded that more than 60 percent of the patients studied were inappropriately placed in state hospitals and could benefit from treatment in other kinds of settings.(11)

States and communities are struggling to meet the basic service needs of their citizens who suffer from a mental illness. According to HHS and HUD, current problems in meeting the shelter and basic living needs of chronically mentally ill individuals stem from a number of causes, not the least of which are instances of localized shortages of housing affordable by low-income people and the stigma against people with mental health problems.

> In addition, however, it has become increasingly clear that there are major problems related to funding patterns, unclear or antithetical legislation, eligibility determination factors, planning and coordinating factors, and program accessibility.(12)

For example, in many of the major federal entitlement programs (such as Medicaid, Medicare, Supplemental Security Income, and Social Security Disability Insurance), certain standards and regulations contain disincentives to appropriate care of persons with a chronic mental illness. Mentally ill persons often do not receive the full benefits of these federal programs and are excluded from eligibility because of restrictive standards of "disability" or "illness" or because of organizational and jurisdictional confusion. Frequently these programs do not intentionally exclude mentally ill persons, but the nature of the disability of these individuals makes it difficult for them to apply for benefits, prove their eligibility, document their case, or cope in general with the confusing application and eligibility determination process.(13) Other essential programs (e.g., Alcohol and Drug Abuse and Mental Health Block Grant, Community Support Program, etc.)(14) are "discretionary" programs, and thus especially subject to cutting, freezing, or elimination efforts (e.g., since 1981 Congress has rejected Administration proposals to eliminate the NIMH Community Support Program and Clinical Training). Reforms or elimination of these discriminatory barriers clearly require action at the federal level.

The outcomes of these limitations, disencentives, restrictions, and discriminatory barriers, according to HHS and HUD,

> [I]nclude the overuse of hospitals and nursing homes, the use of substandard community shelter settings, and the shortage of supervised, appropriate community arrangements.(15)

Thus, mentally ill persons are denied access to services appropriate to their needs. The resulting demand on inappropriate and costly inpatient services causes states to continue directing most of their funding for mental health services to costly state hospitals (in 1983, nearly 65 percent of the $7.1 billion states spent on mental health services was spent on state hospitals(16)). Additionally, this inability to access appropriate services in the community contributes to the presence of mentally ill people among America's growing homeless population.

Mental Health Coalition

Since January 1985, the NMHA has been coordinating the NATIONAL LEADERSHIP COALITION ON MENTALLY ILL PERSONS WHO ARE HOMELESS, an effort of national mental health constituent organizations to address the emergency, intermediate, and long-term needs of mentally ill people who are homeless or at risk of becoming homeless. First convened by the American Public Health Association in late-1984, additional organizations have been invited to join in the coalition's work. The members of the coalition are:

American Nurses' Association
American Orthopsychiatric Association
American Public Health Association
American Psychiatric Association
American Psychological Association
International Association of Psychosocial Rehabilitation Services
International Committee Against Mental Illness
Mental Health Law Project
National Alliance for the Mentally Ill
National Association of Social Workers
National Association of State Mental Health Program Directors
National Coalition for the Homeless
National Council of Community Mental Health Centers
National Mental Health Association
The Committee for Food and Shelter

During its June 1985 quarterly meeting, the National Leadership Coalition heard from representatives of the major federal governmental, public sector, and private sector agencies and organizations(17) as to their plans for dealing with the service and shelter needs of the mentally ill homeless during the impending winter. In testimony addressing the issue "BEFORE THE FIRST SNOW FALLS," speakers representing 18 federal agencies and national organizations left the clear impression that no unified strategy has emerged from the lessons of the past several winters through which to effectively address or resolve these issues. As the chairman of the Coalition, Preston J. Garrison, summarized:

> "I think we've heard a lot about how the public and private efforts are working to meet the needs of mentally ill people who are homeless today. We've heard from the various departments and agencies of [the federal] government...as to what they're doing, the state legislatures and the mayors and the governors associations. So there are a number of individual and partial efforts going on. To the extent that these efforts are comprehensive, I think we could say that most of the efforts are short term, that they're emergency oriented, that they're addressed to trying to meet specific aspects of problems, that in many ways they -- to use the normal cliche we use -- they are bandaids on little bits and pieces of the total problem, that there is very little of a comprehensive effort being undertaken..... What is the national strategy to address the needs of homeless persons, including mentally ill people who are homeless? I think, frankly, we can say there is no national strategy...."(18)

The National Leadership Coalition believes that a much more comprehensive and systematic approach which responds to the short-term and long-term housing, rehabilitation and treatment needs of mentally ill people among the homeless is required. To work toward this end, the coalition has organized four work groups to identify and develop ways the member organizations, and others, can address the needs of mentally ill persons who are homeless or at risk of becoming homeless.

The WORK GROUP ON FEDERAL INITIATIVES has developed a package of administrative and legislative changes needed at the federal level to support efforts by state and local governments, and the private sector, to meet the needs of their homeless population. Fourteen organizations (American Association for Counseling and Development, American Federation of State, County and Municipal Employees, American Mental Health Counselors Association, American Nurses' Association, American Psychological Association, Association for the Advancement of Psychology, International Association of Psychosocial Rehabilitation Services, National Alliance for the Mentally Ill, National Association of Counties, National Association of Social Workers, National Association of State Mental Health Program Directors, National Association for Rights Protection and Advocacy, National Council of Community Mental Health Centers, National Mental Health Association) support the following initiatives as essential to preventing homelessness among mentally ill persons.(19)

1. Presumptive Disability for SSI. Establish a category of presumptive disability under the Social Security disability programs for persons with a serious and prolonged mental illness so as to assist those who are homeless, or at risk of becoming homeless, to obtain essential income benefits that can be used to pay for housing, food, clothes, and other essential support.

2. Pre-release Discharge Eligibility for SSI. Improve pre-release precedures for mentally ill persons being discharged from state institutions to ensure that SSI benefits are payable upon discharge. For a pre-release program to work well, the state mental hospital and the liaison person from Social Security district offices must work cooperatively and they both must be fully cognizant of the pre-release program rules and requirements.

3. SSI/SSDI Outreach. Social Security Office personnel should be engaged in assertive outreach efforts to identify individuals among the homeless who are eligible for federal Social Security benefits. Too often, local Social Security offices do not reach out to shelters and other programs, but instead wait for the homeless to come into their offices.

4. Extend SSI Eligibility for Shelter Residents. Extend SSI eligibility for shelter residents for up to 12 months. This will provide continued assistance (including Medicaid eligibility) to individuals in transitional housing programs.

5. State Inter-agency Planning. Fund state interagency planning initiatives to identify and plan needed services for homeless

mentally ill individuals. A state plan would describe a strategy for the establishment and implementation of a community-based system of care for individuals with a prolonged mental illness, including those who are homeless, so as to provide a full range of housing, health, rehabilitation, employment, mental health and other services.

6. Demonstration Projects Serving Homeless Persons. The federal government, through the National Institute of Mental Health, should initiate demonstration projects serving homeless mentally ill persons, and expand research into the causes of homelessness, demographics of homeless populations, and service needs. The increased knowledge gained from such initiatives will assist localities to develop the range of services individuals with a serious and prolonged mental illness need to live successfully in their home communities.

7. Withdraw Discriminatory HUD Section 504 Regs Which Add to Homeless Crisis. Withdraw proposed regulations which discriminate against mentally disabled persons, issued by the Department of Housing and Urban Development pursuant to Section 504 of the Rehabilitation Act. These regulations could easily be used to deny access to housing for mentally ill persons, and add greatly to the homeless population as a result.

8. Provide Training to Work with Homeless Mentally Ill People. Utilize funds appropriated for the clinical training program of the National Institute of Mental Health to fund on-the-job training for (a) shelter operators and workers on how to recognize, handle and refer to the mental health system mentally ill adults who are using shelters; and for (b) mental health para-professionals and professionals on how to work with the homeless mentally ill population.

9. A Continuum of Housing for Homeless Mentally Ill People. Through the Department of HUD, the Social Security Administration, a new Public Corporation, and tax incentives, the federal government should stimulate greater state action in developing appropriate community housing, linked to appropriate services, for mentally ill persons. A wide range of housing programs are needed: quarterway houses, halfway houses, group homes, supervised apartments, board and care homes, foster/family care arrangements, crisis housing, etc.

10. Provide Residential Services Through the Social Services Block Grant. Amend the Social Services Block Grant to target funds for protective services for homeless persons. General guidelines should require that the agency receiving the funds provide residential programs, with appropriate services, rather than just emergency housing assistance. This emphasis is needed to work towards longer term solutions for those homeless individuals assisted by the program.

11. Funding of Emergency and Transitional Services for Homeless People. Enact legislation to fund emergency and transitional services for homeless men, women and children. Such legislation should provide assistance to hard-pressed local agencies struggling to deal with this domestic emergency. It is certainly not a long-term solution.

The Work Group on Federal Initiatives continues to develop other recommendations for legisaltive and administrative action by the federal government.

The WORK GROUP ON TECHNICAL ASSISTANCE has designed a three-fold mission. Their first task is to disseminate existing information through existing channels. Work group members are gathering information that is currently available about resources and exemplary programs serving the homeless mentally ill population, to be published in the newsletters of the coalition's member organizations. Secondly, the work group has proposed the publication of a clearinghouse newsletter to be made available to shelter providers, mental health agencies, and to others serving the homeless. Such a newsletter would serve as a primary resource for the networking of services, the sharing of information and expertise, and the expansion of support services for the mentally ill homeless and those who assist them. Finally, the work group proposes the development of a clearinghouse, perhaps with an 800 number, which could respond to queries from across the country.

The task of the WORK GROUP ON RESEARCH AND DATA ISSUES is to determine the status of current research in the field of the mentally ill homeless, to look at the difficulties in finding data on the mentally ill homeless (most studies are anecdotal and there are significant problems with lack of commonalities of definitions and methodology), to encourage the collection of more accurate data (e.g., we don't know the size of the homeless mentally ill population, their service needs, effective interventions, the type of personnel who work best with the homeless, who makes up the homeless population, why some mentally ill people become homeless and others don't, etc), and to create a useful database on this population (currently, only limited research is being supported by the federal government, with this through the National Institute of Mental Health's small demonstration program).

The WORK GROUP ON MEDIA AND PUBLIC RESPONSE is charged to address the issues of public understanding of the mentally ill homeless through increased recognition of the related problems of housing, disability benefits, deinstitutionalization, abuse and neglect. The work group is working on identifying a number of guidelines around which to build public information and education initiatives, to disseminate accurate information to the media, and to address public policy issues which impact on homelessness among mentally ill persons.

Senator Kennedy's Bills

Several provisions in Mr. Kennedy's bills address many of the most critically needed reforms in federal programs for mentally ill persons, and incorporate recommendations of the fourteen mental health organizations in their package "Federal Government Actions Needed for Homeless and Other Chronically Mentally Ill Persons Living in the Community."

Medicaid

The most significant provisions concern Medicaid.

An estimated 528,000-600,000 chronically mentally ill persons receive benefits under the federal-state Medicaid program. Persons diagnosed with schizophrenia represent the largest single diagnostic group and consume close to one half of all Medicaid expenditures allocated to chronically mentally ill persons. The total expenditures for chronically mentally ill beneficiaries is estimated at $2.0 billion to $2.2 billion.(20)

However, chronically mentally ill citizens are not now adequately served under Medicaid. The current Medicaid program is structured in such a way that, for mentally ill persons, it emphasizes institutional care for those who may not need it, and encourages (even in non-institutional settings) more intensive care than is often warranted. Of the estimated $2.0-$2.2 billion spent on chronically mentally ill persons under Medicaid, an estimated 87 percent goes for inpatient and nursing home care, with only 6 percent for outpatient services.(21)

The priority given to institutional services for mentally ill individuals by Medicaid is similar for other disabled populations, such as mentally retarded persons. However, in one important respect, Medicaid coverage for these two populations is very dissimilar. Medicaid has no provision to cover intermediate care facility services for mentally ill persons and specifically excludes inpatient care in a psychiatric hospital for those between the ages of 21 and 64.

With the enactment of the Medicaid Home and Community Care Waiver in 1981, states were permitted to substitute community care for institutional care when community treatment would be more appropriate, and also less expensive. However, in developing a waiver request states have found that it is very difficult to use the waiver authority to improve services for mentally ill persons. This is because the only "institutional" services which may be offset against community care costs for mentally ill persons are services provided in psychiatric institutions for those under 21 and over 64.

Thus, currently Medicaid-eligible mentally ill individuals have a limited range of community services available to them, and severe restrictions on long-term psychiatric inpatient care if they are between the ages of 21 and 64. On the other hand, if persons are served in general hospitals then Medicaid will pay for acute care, thus encouraging the use of episodic acute care. This is reflected in the increase in inpatient episodes in general hospitals while there has been a sharp decrease in state hospital inpatient episodes.(22)

Expansion of Medicaid coverage for the less intensive services which are provided in the community and designed to prevent institutionalization is crucial. These services include especially: case management, psychosocial rehabilitation, residential programs, asssitance with housing and other supportive services.

The NMHA, therefore, strongly supports the inclusion of case management services and community and home-based care in Medicaid, as Senator Kennedy's bill proposes. These will go a long way is assuring access to appropriate services, thereby avoiding costly use of unesessary inpatient services.

Case management is the glue of an effective community support system. Needed is one persons or team who is responsible for establishing and remaining in contact with the chronically mentally ill disabled individual on a continuing basis, regardless how many agencies are involved. Realistically, this person must be ready to play whatever roles the situation may require -- outreach worker, counselor, therapist, broker, advocate, teacher, data manager, community planner or administrator. Effective performance of these functions requires a limited caseload.

Community and home-based services form the foundation of an effective community support system. Each community needs to provide access to pscyhosocial rehabilitation services, including community-based pscyhiatric and pscyhological services; a wide spectrum of community-based living arrangements offering varying degrees of supervision, assistance and support, and linked with appropriate mental health, health, social rehabilitaiton and other appropriate services; opportunities for training in community living skills; recreational and social opportunities; and vocational evaluation, training and placement services. Rehabilitation services under the community and home-based provision should include comprehensive services for independent living as described in Section 702(b) of the Rehabilitation Act. We are particulary pleased to see the inclusion of prevocational services under this provision. Specialized prevocational services enhance independence, productivity, and community integration of seriously mentally ill persons. They include employment training, support necessary to maintain the employment of such individuals and other training and therapeutic activities.

SSI/SSDI

The Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI) programs have been major sources of subsistence for persons with a chronic mental illness. These payments are used by the individual to help defray some of their living expenses in residential facilities (e.g., boarding homes, foster homes, group homes, and supervised apartments). Without these funds to support them in the community, many of these persons might otherwise remain in institutions or be placed in nursing homes.

In November 1982, approximately 396,000 persons were receving SSI benefits and 243,000 were receving SSDI benefits for reason of mental illness. The average benefits award in 1982 for SSI receipients was $284 per month and for SSDI recipients, $454 per month. The total SSI expenditures (inlcuding federal payments and state supplementation) for mentally ill recipients are estimated nationally at $1.54 billion. The total federal SSDI expenditures for mentally ill recipients are estimated at $1.55 billion.(23)

Although SSI has helped many mentally ill persons, because of the low rate of federal payment and the shortage in some areas of low-cost housing, there is an incentive to return individuals to institutions where the costs of food, clothing, and shelter are paid, rather than trying to maintain them in the community.

Delay in SSI eligibility determination can exacerbate housing problems for chronically mentally ill persons (resulting in homelessness for some. Appendix, St. Vincent's Shelter). This is of particular concern to individuals awaiting cash assistance to leave state institutions, and persons in the community in danger of institutionalization because of lack of funds to purchase shelter, food, and medical care. Additionally, financial stress may complicate an individual's emotional problems at a time that is critical to community adjustments. Expensive rehospitalization is a likely result.

In addition, the SSI program does not make payment for months, throughout which, an individual is an inpatient in a public medical treatment facility (or the payments are reduced to $25 a month if the facility receives or expects to receive 50 percent or more of the cost of the individual's care from Medicaid programs). Because this population may need frequent short hospitalizations that cover one or more full calendar months, they are often financially unable to maintain a consistent residence.

We are therefore particularly pleased to see in Senator Kennedy's bill the provisions (a) providing for presumptive diability for chronically mentally ill persons who are about to be discharged from an institution, are at risk of institutionalization, or are homeless, (b) assuring continued SSI benefits during short periods of hospitalization, and (c) making SSI benefits available while a chronically mentally ill person is a resident of a public transitional living facility.

The NMHA also supports the provision assuring continued Medicaid coverage for mentally ill beneficiaries of SSI. Recipients of SSI also are eligible for Medicaid benefits. However, an SSI recipient who earns income in excess of $325 a month loses both SSI cash benefits and eligibility for Medicaid. A provision in the Social Security Act, Section 1619, that remedies this problem by permiting such a person to retain his or her Medicaid eligibility while he works, expires June 30, 1987.

Nursing Homes

While large numbers of mentally ill persons are being inappropriately served in state hospitals, according the the Departments of Health and Human Services and Housing and Urban Development, a much larger number of individuals are inappropriately housed in nursing homes.(24)

Nursing homes are considered institutional in character because they reinforce dependency and are more or less isolated from the mainstream of community life. Elderly persons are not the only ones who reside in nursing homes, as Lawrence's story in the Appendix demonstrates. Most are designed primarily for physically ill and disabled persons. Consequently, most lack staff trained to deal with mental health problems. According to HHS/HUD, many nursing homes do not meet basic safety or patient care standards. The deficiencies and problems of nursing homes for the mentally ill have been well documented in a number of congressional and other reports. Among these are a 1976 supporting paper of the Senate Special Committee on Aging, Subcommittee on Long-Term Care, entitled "The Role of Nursing Homes in Caring for Discharged Mental Patients," the 1977 report of the General Accounting Office (GAO) entitled "Returning the Mentally Disabled to the Community: Government Needs to Do More," and the 1982 GAO report entitled "The Elderly Remain in Need of Mental Health Services."

Despite the consensus that nursing homes are generally inappropriate settings for people with chronic mental illness, they remain the largest single shelter for such individuals. According to HHS and HUD, the reasons for this stem primarily from federal reimbursement policies and include the following:

> "o Mental health agencies lack sufficient resources to maintain hospital facilities and develop systems of community care; thus, they must rely on other departments such as welfare to provide fiscal resources.

"o Medicaid reimbursement is available (with certain restrictions) for otherwise appropriate placement of the mentally ill in SNFs ot ICFs so long as they cannot be classified as "institutions for mental disease," but is not available for other types of nonhospital settings that provide room and board.

"o Placements in ICFs and SNFs are convenient because such facilities assume total responsibility for the residents living there, providing food, clothing, shelter, and various health and social services. It takes considerable time and effort to coordinate such services in the community.

"o Certain restrictions in the SSI program (e.g., the prohibition of SSI payments to persons in publically owned or operated facilities housing over 16 persons) and the reduction of SSI payments (in cases when support is provided by State agencies) create an additional incentive toward nursing home placements. This exists because their needs are met by the institutions and the SSI program was not intended to assume this responsibility."(25)

The provision in Senator Kennedy's bill requiring the establishment of standards for appropriate care and treatment of mentally ill persons in nursing homes will help assure their access to such services.

Discharge Planning

The discharge procedure is crucial in enabling patients to successfully make the transition from inpatient facilities (both public and private) to more independent living in the community. Individualized programming is an essential part of this procedure. The simplest kind of individualized programming involves placing a patient in a program that is compatible with his or her current level of functioning and provides resources for skill development. However, the discharge process is frequently fraught with problems. Patients are often simply dropped off at Community Mental Health Centers, at shelters for the homeless, or abandoned at bus stations or on the streets (see Appendix, St. Vincent's Shelter). Many have insufficient assistance to obtain income support benefits to which they are entitled and so cannot afford housing.

We are therefore pleased to see that Senator Kennedy's bill requires all hospitals to assure discharged patients have a plan of care established and a case manager assigned prior to discharge.

Housing

The cornerstone of any service system for chronically mentally ill persons is a foundation of community residential facilities. The lack of a sufficient number and variety (see Appendix, St. Vincent's Shelter, Account of a Young Woman With Schizophrenia, Services - or the Lack of Them) of residential accommodations is one of the major deficiencies in our present service system, as well as one of the leading contributors to homelessness among chronically mentally ill persons. The 1983 study by HHS and HUD identified the lack of adequate housing as "perhaps the major unmet need of the chronically mentally ill." A 1984 report to the New York State commissioner of mental health notes that "the single most critical factor which prevents effective service coordination and implementaion of rational discharge planning is a lack of provision for adequate housing for the chronically disabled."(26) As a result, many mentally ill persons reside in board-and-care homes, single-room-occupancy hotels, shelters, and other dilapidated settings in addition to the streets.

Thousands of people currently in hospitals, nursing homes, shelters, and other inappropriate sites could function more independently in residence clubs, group homes, family foster care, or supportive apartments if adequate numbers of such programs were available -- all at a total cost, according to HHS and HUD, "that would be less than the costs of current arrangements."(27) What is needed, the HHS and HUD study concludes,

> is a <u>continuum</u> of residential options for this population, ranging from hospitals to nursing homes, to group homes, to foster care, to shared apartments, to independent living. No single residential option can meet the needs of all the population.(28)

The provisions in Senator Kennedy's bill concerning housing will greatly assist in developing such a continuum of residential options.

State Planning

Realistic planning is critical if the challenge is to be met of organizing the great diversity of mental health and support services and opportunities in each state into a meaningful and effective system that mentally ill persons can access. It is important that such planning be across state agencies, including, besides the state mental health authority, the state medicaid office, the state housing authority, the vocational rehabilitation agency, the education department, and other state and local agencies that make and implement decisions which impact on the service needs of mentally ill persons. Strong consumer participation in such planning efforts is essential.

In closing, Mr. Chairman, what better way to summarize the need for federal action than the words of a mother of a young woman with schizophrenia (Appendix):

> "I am a fiscal conservative. I do not believe in asking for government handouts with out exerting my own energies to match federal funds with state and private funds.... We are not sitting idly by and just dreaming. All we ask for is a fair share of federal money to help eradicate this devastating illness. So far, we have been almost ignored."

Mr. Chairman, the National Mental Health Association appreciates the ongoing leadership of this committee in improving those programs within the committee's jurisdiction that benefit mentally ill persons. We are pleased to have had this opportunity to appear before you today, and look forward to continuing to work with the committee in improving access by mentally ill persons to much needed appropriate, community-based mental health services and support systems.

NOTES

1. In a recent position statement representatives of the 55 state and territorial mental health agencies said that "Congress has failed to follow through on funding this country's commitment to quality care for the mentally ill -- a policy first enunciated in 1963 and reiterated in 1980." Further the state directors said that "recent events raise the possibility of further reductions in the states' ability to provide care" citing a recent U.S. Supreme Court decision backed by the administration disallowing partial reimbursement under Medicaid for mentally ill persons living in community settings, potential application of the diagnostic-related group prepayment plan which would result in "the literal dumping of general-hospital psychiatric clients onto the public sector at an astronomical cost", and the federal government's refusal to cover part of the cost of treating mental illness for poor patients aged 22 through 64. National Association of State Mental Health Program Directors, State Mental Health Agencies Score Congress on Failure to Support Quality Care of the Seriously Mentally Ill, July 10, 1985.

2. Several attempts have been made at identifying the comprehensive range of services and supports required by chronically disabled persons living in communites. They usually include the following: housing, income support, medical follow-up/medication monitoring, crisis management, better access to hospitals, case management, psychosocial programs, training in life skills, vocational training/work activity, family support services, self-help network, transportation, leisure activity,

and education of community. Freedman, Ruth I. and Moran, Ann. Wanderers in a Promised Land: The Chronically Mentally Ill and Deinstitutionalization. Medical Care, December 1984, Vol. 22, No.12, Supplement, at S21.

3. 768 Community Mental Health Centers were funded under the Community Mental Health Centers Act. The Community Mental Health Services Network: A Statistical Profile. Rockville, MD: National Institute of Mental Health, February 1983. A recent survey found 4,002 service sites (1,572 entities and 2,430 satellite locations) providing community mental health services. National Registry of Community Mental Health Services '85, Rockville, MD: National Council of Community Mental Health Centers, 1985. Nearly 1,000 organizations have been identified as providing pschosocial rehabiltation services in at least three of the following categories: vocational, residential, social/recreational, educational or personal adjustment services. Organizations Providing Psychosocial Rehabilitation and Related Community Supoport Services in the United States 1985, McLean, VA: International Association of Psychosocial Rehabilitation Services, 1985.

4. Footnote 2 at S14.

5. Okin, Robert L.: State Hospitals in the 1980s, Hospital and Community Psychiatry 33:717-721, 1982.

6. Letter of Harry C. Schnibbe, Executive Director, National Association of State Mental Health Program Directors, August 29, 1985, cited in Draft Outline of Present Mental Health Conditions and Services, Future Mental Health Services Project, National Mental Health Association, October 1, 1985 (unpublished)

7. National Institute of Mental Health, Series CN No. 2. Characteristics of Admissions to Selected Mental Health Facilitites, 1975: An Annotated Book of Charts and Tables. DHHS Publication No. (ADM)81-1005, 1981, at page 93.

8. Report on Federal Efforts to Respond to the Shelter and Basic Living Needs of Chronically Mentally Ill Individuals, Department of Health and Human Services and Department of Housing and Urban Development, February 1983.

9. Toward a national plan for the chronically mentally ill. Report to the Secretary by the Department of Health and Human Services Steering Committee on the Chronically Mentally Ill, December 1980. Rockville, MD: Department of Health and Human Services, 1981, DHHS Publication No. (ADM)81-1077.

10. Final Report of the Governor's Select Commission on the Future of the State-Local Mental Health System, State of New York, November 1984.

11. Footnote 5 at 718.

12. Footnote 8 at i.

13. Footnote 2 at S35-S40.

14. Other programs are the NIMH Clinical Training Program, the NIMH State Interagency Planning program, Protection and Advocacy for Mentally Ill Persons (pending bills S.974/H.R.3148), Education of All Handicapped Childrens Act, Social Services Block Grant, HUD Section 202/8 housing assistance programs, vocational rehabilitation, statewide independent living services program (Part A of Title VII of the Rehabilitation Act), legal services supported by the Legal Services Corporation, the developmental disabilities program, general revenue sharing, community development and services block grants, food stamps, Older Americans' Act programs, among others.

15. Footnote 8 at i.

16. Footnote 6.

17. Representatives from the following agencies and organizations reported their activities to the National Leadership Coalition: Federal Task Force on the Homeless (also reported on activities of the Department of Labor and ACTION/VISTA); Alcohol, Drug Abuse and Mental Health Administration/National Institute of Mental Health; Department of Housing and Urban Development; Social Security Administration; Veterans Administration; National Governors' Association; National Conference of State Legislatures; U.S. Conference of Mayors; National League of Cities; and The Committee for Food and Shelter. Transcript, The National Leadership Conference on Mentally Ill People Who Are Homeless, "Before The First Snow Falls" Quarterly Meeting, National Mental Health Association, June 10, 1985.

18. Footnote 17 at 217-218.

19. The detailed package of the proposals "Federal Government Actions Needed for Homeless and Other Chronically Mentally Ill Persons Living in the Community," is available from the National Mental Helath Association (1985).

20. Steele, R. Estimated medicaid expenditures for health care of people afflicted with chronic mental illnes. Project summary presented at the Conference on Chronic Mental Patients in the Community, December 4, 1982; Study Conducted for HCFA (Contract No. 500-80-0014), Birch and Davis Associates, Inc., Silver Spring, MD.

21. Footnote 20.

22. Kiesler, Charles A.: Public and Professional Myths About Mental Hospitalization: An Empirical Reassessment of Policy-Related Beliefs. American Psychologist 37:1323, 1982.

23. Footnote 4 at S36-S37.

24. Footnote 8 at 11.

25. Footnote 8 at 12.

26. New York State Office of Mental Health: Committee Report to the Commissioner of Mental Health. Albany, Jan 1, 1984 cited in Lipton, Frnk R. and Sabatini, Albert. Constructing Support Systems for Homeless Chronic Patients, in The Homeless Mentally Ill: A Task Force Report of the American Psychiatric Association, 1985; at 161.

27. Footnote 8 at 17.

28. Footnote 8 at 17.

National Mental Health Association
1021 Prince Street • Alexandria, Virginia 22314-2932 • (703) 684-7722

APPENDIX

TO

STATEMENT CONCERNING ACCESS TO MENTAL HEALTH SERVICES

BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

BY THE

NATIONAL MENTAL HEALTH ASSOCIATION

Wednesday, October 9, 1985

Earlier in the year, the National Mental Health Association sought from its nationwide network personal stories concerning problems experienced in accessing appropriate mental health care and support services. Following are four stories selected from the letters NMHA received.

As the letters illustrate, there is tremendous stigma against persons with+ a mental illness. Therefore, to needless publicity, NMHA has provided the family members with anonymity, even when not requested.

I. Services - or the Lack of Them
By a mother of a 26 year old woman

II. Lawrence's Story
By his mother

III. Account of a Young Woman With Schizophrenia
By her mother

IV. St. Vincent's Shelter
By Sister Patricia McKeon

Salt Lake City, Utah
July 25, 1985

JOHN AMBROSE
C/O NAMI
1021 Print Street
Alexandria, VA
223-14-2932

Dear Mr. Ambrose:

This letter is in response to a request for information regarding services (or the lack of them) for mentally ill family members in our area. It is my understanding that certain members of the Senate are attempting to appropriate funding to help these people nationwide. I would like to share some of the problems that my daughter has encountered.

My daughter is 26, and she has been in and out of hospitals and treatment facilities for the past five years. She has a personality disorder together with chronic depression. Until she was 23, she was covered by our medical insurance, and though we had to suplement it, for the most part she was able to obtain fairly adequate care. However, since that time, she has found it necessary to get on Social Security, as our family was unable to support her and pay for the extra medical and psychiatric services she required. Since her father died last year, she has been able to draw on his Social Security.

One of the biggest problems she has encountered is being unable to afford a psychiatrist of her choice and regular, ongoing therapy with the same doctor. It seems that when a mental patient goes to the County Social Services for help, he/she is assigned a therapist at random from whomever is available, whether or not that particular therapist is knowledgeable about the specific type of illness the patient is afflicted with. Doctors change and move around, and residents, many with little experience and still in their own learning process, are constantly on rotation. If the therapist moves from the geographical area or facility where the patient is being treated, the patient, in most cases, cannot follow him/her. On at least two occasions she has developed a trusting relationship and rapport with a therapist and has been making good progress, only to have the therapist move on.

It is a major trauma to mental patients when they must change therapist and begin all over again with a stranger. The most constant help she has been able to receive has been from staff workers in the hospitals and residential treatment facilities where she has been a patient. However, even these dedicated staff workers are overworked, and there is a constant turnover of qualified personnel. A situation like that makes it very difficult for a mental patient to cope with. It causes a patient to regress, feel insecure, and it certainly shows down the progress and the road to recovery. It takes months, even years for these people to learn to trust and feel somewhat secure in their relationships with another therapist. I realize that psychiatrists and psychologist in private practice also occasionally relocate; however, the incidence is much higher among government supplemented programs.

There are two main residential treatment facilities in the Salt Lake area. ARTU (Adult Residential Treatment Unit) seems to be the best and most effective unit available to Medicaid-Medicare patients. It is structured, and they have obvious goals to help the residents become responsible, productive citizens in the community. They provide both group and staff support. However, it is very diffucult to get into this facility, or any other for that matter. When one is in a crisis situation, having to wait long periods of time just to get a "bed" can greatly worsen the situation and sometimes be devastating to the mentally ill individual. On several occasions, having to wait long periods of time for a bed in one of these faiclities has resulted in our daughter having to be hospitalized. Had there been a place available for her, the expense and trauma of going to the hospital could have been avoided.

Another major problem that she has encountered is the fact that all of the residential facilities are geared toward lower functioning individuals. Most of the time she functions quite well. She is intelligent and, under most circumstances, she does not have to be heavily medicated. However, when she does find it necessary to go to a residential facility and they do have room for her, she cannot relate to most of the other residents because most of them are lower functioning.

The programs at ARTU and the other local programs are primarily geared to teach residents such things as grooming, appropriate behavior, use of public transportation, job search or apartment search, and cooking. She finds little to relate to in this type of program and soon becomes bored and anxious to leave. When she or any other higher functioning adult, leaves too soon she usually ends up in the hospital for a lengthy stay and more expenses. She is not the only one with this problem. I know of several other higher functioning individuals with mental health problems, both young and old, who face the same difficulties.

In my opinion, there is a great need in the community, the state, and the nation for not only more adult residential type treatment facilities for the mentally ill, but also for facilities for higher functioning adults. IF SUCH FACILITIES WERE AVAILABLE, IT WOULD NOT ONLY SAVE MILLIONS OF DOLLARS IN HOSPITAL AND MEDICAL EXPENSES, BUT IT WOULD PREVENT UNTOLD MISERY, ANXIETY AND HEARTACHE FOR MENTALLY ILL PEOPLE WHO NEED HELP TODAY, TONIGHT, RIGHT NOW, AND NOT NEXT WEEK, NEXT MONTH OR NEXT YEAR.

Whatever you can do to appraise the situation and inform the legislators or powers that be regarding this great need would be most appreciated. I firmly believe that the keyword is PREVENTION!

Sincerely,

What of Mental Health Treatment Facilities?

<u>Lawrence</u>, as a child and as a teenager was active in sports, played the violin, and did well in school; was well accepted by his peers. He tended toward over achievement. His father's death added to his strain.

His illness developed in early college years. He graduated from college and, under great stress, held down three different good jobs before a pretty complete break down. He had functioned poorly with little and ineffective medical attention from an internist who made no psychiatric referral; was voluntarily admitted to a mental hospital through urging of the family. Still he was unable to comprehend the nature of his illness.

Later he was committed to the State Hospital where his utmost intent was to escape from a degrading facility. This he did on several occasions when he would work at any job possible until finally picked up by police and returned to the hospital.

At the hospital he developed a good relationship with but one therapist and cooperated in holding down a messy job for a time. That therapist was transferred.

His final discharge came when he failed to comply with a very long list of dos and don'ts required by a psychologist. He was told to leave, get a job, and find a place to stay. That night he took <u>all</u> of his meds and landed in E.R. of a teaching hospital. After a brief stay there he was placed in a nursing home.

The family, for the most part, was treated by staff as a bother. There was no contact with them upon discharge or nursing home placement. Much, very much could be told of the sufferings of all concerned. This is not a family of wealth and the mother and two other children worked hard for a living and an education. Lawrence had, early in college years, taken a heavy load of credits and held two jobs.

Nursing home existence has trained him well in being dependent. His self-respect, esteem and confidence have been shattered. Mental health programs are inadequate when it comes to off-setting the discouraging living facilities.

In the community there are suicides by the mentally ill; but many deaths occur before one comes to die.

WHAT WOULD BE AN IMPROVEMENT IN PROGRAM AND PROCEDURES?

Residential alternatives well staffed and offering something to do; a section consisting of sheltered work shop opportunities, appropriate goals to achieve. A continumm plan where clients are encouraged to work at their level of capacity, to become what they are capable of becoming.

A place where it is recognized that these are still people; people with social, emotional, and achievement needs. They need hope. The source of anyone's strength is his hope; not his fears and his distress. "Hope once destroyed leaves man prey to all the fiends of hell."

Give them new experience, recognition, response and a sense of being cared about.

Mental Health Programs need a lean, efficient staff; need to guard against being staff oriented, where program, not the client, is what's important.

Rehabilitation programs should offer cooperation and help for the mentally ill being acceptably placed and supported in suitable jobs.

All mental health endeavors should, oblivious to credits, band together in helping to achieve public awareness of this tremendous, wasteful problem; wasteful in how money is spent, in family energies and finances, and in the lives of some of our intelligent, not second class, but first class citizens.

Training of therapists and research need to be greatly increased and upgraded.

This article was written anonymously. It is written this way because the persons involved are aware of the tremendous stigma against the illness called schizophrenia. However, those who are submitting it have the names and addresses of the people involved, should it be necessary to contact them.

I. INTRODUCTION

An Analysis of Current Medical Care for Persons Afflicted with Schizophrenia

Weakness of County and Private Mental Health Systems with Suggestions for Improvement

Written by a Mother of a daughter with Schizophrenia.

The following pages are an abridged account of a young twenty-four year old girl diagnosed with schizophrenia. The author, who is the mother of the young woman described in these pages, has tried to be accurate and fair with her analysis of both the public and private sectors of medicine in the treatment of this illness. She has reached some of the following conclusions:

"Schizophrenics will continue to be fourth-class citizens, leading twilight lives, shunned, ignored, neglected" (1) unless the families and friends of those who are afflicted rise up and demand the following:

1. Much more money for responsible research. Better trained psychiatris
2. More money for better housing facilities.
3. More money to educate legislators and the public about this illness.
4. More and better sheltered workshops who will hire these people.
5. Private employers who will hire these people.
6. More friends who will treat these people with tolerance and respect, rather than ignore them as modern day lepers.

Schizophrenia is an illness which is no respector of persons, races, religions or economic classes. It is an illness which operates on about one-twentieth the amount of money given to cancer or to arthritis. It is an illness which is forty times more prevalent than muscular dystrophy. (2) It is an illness which, like diabetes, probably cannot be completely cured, but can be brought under good control. It is not an illness of extreme violence as is frequently assumed---rather the victims are frequently shy and withdrawn.

If this illness is brought under control it will be because more funds, better medical help, and enough friends become available to make this improvement possible.

Perhaps we should ask ourselves the age-old question---"Am I my brother's keeper?" Everyone of us must ask .. question in the recesses of our own heart and mind. Then we must *do* something about it.

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(1) E. Fuller Torrey, M.D. *Surviving Schizophrenia: A Family Manual* Harper and Row, Publishers, New York, p.228

(2) E. Fuller Torrey, M.D. *Surviving Schizophrenia*, p.226

II. TRUE ACCOUNT OF A YOUNG WOMAN WITH SCHIZOPHRENIA

Late on a wintry December afternoon my husband recieved a call from our daughter who was attending a private, religiously owned university. In her voice was the sound of alarm. "Dad," she said, "please come and get me. Something has happened." My husband complied immediately with her request. Later that evening, within the confines of our home, we discovered indeed that something serious had happened. We immediately got medical help, and we reasoned that with this help and a great deal of love our daughter would recover. Perhaps within six months she would be able to return to school and complete one more semester so she could receive her batchelor's degree.

About five years have elapsed since that time. Three of those years have been spent going from professional psychologists to social workers to medical psychiatrists. We consulted about fourteen professionals. Most of them could not give us a definate diagnosis. One of them said that she had an "attentional deficit disorder". Another said that if we would just give her more affection her condition would greatly improve. Another said that we must be more firm with her. Finally a competent medical psychiatrist at the University of Utah said, "Let's put her in the hospital for three weeks and quit guessing. We shall observe her carefully and give her medical tests. Then we will know with more conviction what is wrong." We followed his suggestion. At the end of three weeks he confirmed what others had begun to suspect---she was a victim of chronic paranoid schizophrenia.

This term is misleading. It is a catchall for what will probably come to be considered as a variety of different but similar diseases. Recent research indicates that schizophrenia is probably a bio-chemical imbalance resulting in a "thought disorder". All we knew was that our daughter's personality had changed dramatically. Once she had been an elected class officer and had been classified as a gifted student. Once she had won a creative writing contest for the entire state. Once she had started college on an academic scholarship. Now she could not concentrate to complete a single course. Once she had been the recipient of many tennis trophies. Now she could hardly play for ten minutes. As an infant she became extremely animated when she was in the company of others. Now, if people entered the house, she often retreated to her bedroom. She had been the first of our children to go out and get a job. Now she was unable to hold one for more than three weeks. Sometimes she voluntarily quit because she felt she would be fired. Sometimes the supervisors simply said she was making too many mistakes, and they would let her go.

We asked the professionals what we should do, they were vague in their advice. They experimented with various medications. With every one of the medicines she developed most undesirable side effects (gross muscular contractions of the mouth) and had to be taken off these medications. We asked if there were available private facilities where she could get concentrated treatment. The only such facilities available were very rare and scattered throughout the country. Costs varied from $5,000 per year to well over $100,000. Our medical doctor felt that these facilities were not much more effective in treatment than were the public facilities. With this announcement, we decided against using these more exorbitant private facilities.

The private medical community had failed to get her well. We now turned to the public sector and started using the facilities of our own State/County Mental Health system. We used two patient and caring therapists who saw her in their office once a week for a 50 minute session.

As the months dragged into several years, we at times would notice patterns of improvement. Our daughter, on her own, obtained a job in a sheltered workshop. She felt glad to be doing something outside of the home. This was indeed improvement. There were some problems with the job, but she would do her best when she could work with a few trusted friends and an understanding supervisor. Even with this improvement, the therspists from the County Mental Health system felt that she was still too dependent upon us. They felt that she would do better if she would learn some independent living skills. They suggested that we place her in a twenty-four hour live-in facility operated by County Mental Health.

On two seperate occasions we placed her in this Adult Residential Treatment Unit. The purpose of these visits was to see how she would adjust to the program. On both occasions she had strong negative reactions. When she returned home she described her experiences as follows: "Mother, some of the therapists were excellent people, but the ill people in that facility will never help me to get well. Most of them were just being released from the hospital after having had complete psychotic breaks. I have not had a psychotic break. I do not feel that I am as ill as they are. Most of the young men were so withdrawn that I could't carry on a converstaion with them, even if I wanted to." One boy approached her on the first evening and suggested to her, "Let's get out of this place and have a night on the town". She found such boys intimidating, and the continual importuning from this boy, a transient from Chicago, frightened her. Another older resident approached her and made some inappropriate sexual advances. Though he was stopped from doing this by one of the therapists, my daughter was already so frightened that she couldn't utter a word, let alone push the man away.

Altogether there were about twelve young men in the facility and only two other women. One of the women was so withdrawn that even the therapist could not get her to talk. The other was a schizophrenic in her late sixties. I doubt that either of these women could have helped my daughter. Janet stated that the facility was very crowded at times, particularly in the evening when a group of about thirty other outpatients was brought in. All would hover around the television instead of interacting with one another. Janet also stated that the facility was filled with cigarette smoke that was so thick that she had to cut her way through it. She hated having to sleep on the same floor with the boys and share the same bathroom with them since she did not feel safe. She said, "Mother, you want me to become more social. How can I develop social skills with these people who are even more ill than I am? They are not role models. Their language is crude and I have nothing in common with them".

We know our daughter may have been over-reacting. We also know there was some truth in what she said. We felt her gentle personality would not be able to adjust to these living conditions. We felt that is we placed her there, we would have to handcuff her to get her to go. Also there was the real danger that she would run away. (She had done this on two previous occasions.) At length we were able to find a good, wholesome family who specialized in taking in young people with problems. We placed her there instead, but, of course, we payed premium fees. She did however, make some progress. To us it was worth the cost. But we could not continue these fees for very long. She stayed at this home for four months. After that we have paid some psychology students to live with her. Most of the American population could never have afforded the fees we have paid.

III. An Analysis of the Medical Care Given to our Daughter, A Schizophrenic

I have been asked to write my reactions to the County Mental Health System, how it failed my daughter, and what could be done to make it more effective. Let me make it clear that it was not a complete failure. The two County therapists she used were competent professionals. But for schizophrenia, much more is neede than private counseling. Persons with schizophrenia need twenty-four hour structured care, sometimes for a few months, sometimes for a few years. I do not think our daughter could ever have made an adjustment to the existing County facility. However, with more money this facility and the others could be greatly improved. In the private sector, again, they are few in number and exorbitant in cost---available only to the top two or three percent of the population. We are not in that category.

IV. Some Suggestions for Improvements

1. Most of all more money os needed for responsible research to determine accurate causes of the illness and more effective ways of treating the illness. I feel that there is a great injustice when I learn that for cancer and arthritis researoh funds amount to between $150 and $200 per year per patient. In the field of schizophrenia only about $7.00 is spent per year per person. I wonder about the justice of granting billions of dollars for outer space research when the ill who are with us are being ignored. The Federal Government is pouring millions of dollars into the artifical heart program to help the elderly. Should we not be putting at least an equal amount of money into helping the young---those who are in the prime of their lives? Schizophrenia is not a rare disease---and dedicated researchers must find answers as to causes and cures.

2. County Mental Health Systems need more money so they can build a range of facilities---some for the very ill who are just emerging from hospitals, other facilities for those who are just beginning to get better. Facilities are also needed for people who can almost care for themselves, but who still need acess to medical and psychiatric support if they regress. In the facility in which my daughter was placed, there were sick people of all degrees, but most were so ill that a conversation with them was almost impossible.

3. States and Counties need more money so that they can build some seperate facilities for young men and for young women. I believe it wholesome to comingle the sexes for social activities, and for eating together and participating in therapy session and working together. But I do not believe that single, unmarried and ill people of both sexes should have to sleep together on the same floor and share the same bathrooms. One mother reported to me that her son was caught in an illicit relationship with another female in the facility in which they had been placed. Another therapist admitted to me that occasionally this does happen. While I hope that this is the exception, it does occur. Even though my daughter is mentally ill, even though she lives in an era

of free love, she does not want to participate in this uncommitted life style of living. It is in great conflict with her religious values which she still clings to. She realizes, though, that because of her illness, she is vulnerable to sexual advances. This was one of the very real fears she had when she tried out the county facilities.

4. I believe, too, that residential facilities funded with government money should not use cigarettes as token rewards for good behavior. While these ill residents live in these facilities they frequently are encouraged to smoke---even when they have not smoked before they entered the home. I am convinced, as is the Surgeon General's Office, that the evidence is overwhelming against the use of tobacco. I feel it is morally wrong to care for the mentally ill individuals, and to contribute to other health problems, such as cancer, heart disease, emphysema, chronic bronchitis, etc. by encouraging them to smoke. I suppose for patients who are already addicted to this habit, separate smoking areas could be provided. But even these patients should be given support in helping them to "kick the habit", as is done with patients who are addicted to other drugs. Particularly, for those individuals who have never smoked, they should have the right to live in a smoke-free atmosphere.

5. I believe that more money is needed to launch a campaign that would erase the stigma against schizophrenia in the general population. Currently schizophrenics are regarded as the lepers of society. They are shunned and excluded from living in certain areas. They are not hired for jobs. Until they are given a chance, they will never make progress.

6. I believe that in county facilities patients should not be belittled for private religious beliefs. During my daughter's short stay in this facility she tried to participate in one of the therapy sessions. Once, while she was awkwardly trying to express herself she used the word 'religion'. She was promptly told by the group leader that no conversation would be acceptable if it contained anything pertaining to religion. In this country we certainly believe in freedom of religion. But do we believe in no religion at all? I hope not!

V. Defense of Asking for Federal Money

I am a fiscal conservative. I do not believe in asking for government handouts without exerting my own energies to match federal funds with state and private funds. I personally have contributed generously to our own local chapter of the National Alliance for the Mentally Ill. Our organization annually appears before our own state legislature reqestin some State money. The parents in our community have gone out and gotten retail stores to contribute furniture, beds, mattresses, chairs etc. to furnish some cooperative housing for some of the mentally ill. Our group has sponsered bazaars to raise money. We are sponsoring TV spots and making films for television and radio to help eliminate the stigma against mental illness. We are not sitting idly by and just dreaming All we ask for is a fair share of federal money to help eradicate this devastating illness. So far, we have been almost completely ignored.

The prognosis for schizophrenia by some is regarded as very poor. However, there are enough examples to know that with adequate support and hope---they <u>can</u> improve themselves, they <u>can</u> be self-supporting and be contributing citizens to society.

St. Vincent DePaul Place

617 Main Street, P O Box 398, Middletown, CT 06457
(203) 344-0097

St. Vincent's has operated a shelter for the homeless for the past three years. During that time we have had a policy that admission is on a first come, first served basis daily. Guests may return as often as necessary there is no limit to length of stay but they must leave each day and return each night on the same first come... basis. During those years we have sheltered hundreds of guests and those that stay the longest and are least successful in finding permanent residence are the mentally ill. At this point in time we have a chronic population at the shelter who are unable to get and/or keep a room.

The gentleman who was our first guest three years ago is standing in line at this moment waiting for the shelter to open. That means he has stood in line almost one thousand (1000) times. All his belongings are on his back. He was released from the State Hospital that is located in this city and has been dependent upon St. Vincent's ever since with the exception of a short period when he returned to the hospital and then was released back to the street.

We attempted to get him on welfare but were unsuccessful because the man had no sense of time and was unable to keep an appointment. Each time we would get him into the process he would slip through and the City would throw out his application and we would be back to square one. It took over two years before he finally completed the process. Now the bigger process to get his disability benefits.

The man has been rejected from local half-way houses because "his level of functioning is not high enough". The State Department of Mental Health was requested to help get him a place and I was told to "take him to the out-patient clinic at the hospital".

Our shelter is filled with comparable cases. If they are able to get a low income apartment they often lose it in a short time because they have no support services to help trouble shoot for them and consequently decompensation and lose of the apartment become a circular cause-effect event. Many of them have become self-medicators and are involved in substance abuse problems. These dually afflicted people have the most difficulty in finding and keeping a rent.

Many mentally ill people have symptoms that are so obvious that no one will even consider them for a tenant. One gentleman who is very big and has a very loud voice talks out loud all the time. He was able to work until recently when he injured his back. At that time he slept in the shelter each night and received a pay check each week. He had the money but no one would rent to him because of his symptoms.

A Ministry of the Catholic Diocese of Norwich

St. Vincent DePaul Place

617 Main Street, P O Box 398, Middletown, CT 06457
(203) 344-0097

The problems of the homeless mentally ill include:

Discharge to the street from State Hospitals;

Probate court decisions that have only letter of the law enforcement and concern of the individual as secondary;

No help in obtaining disability benefits while in the hospital but being forced to get through the bureaucratic maze on their own after discharge;

Lag time between applying for welfare and actually receiving money;

The 'catch twenty-two' situation of having to have a rent receipt before being able to apply for a rent subsidy;

Lack of coordination of services to the deinstitutionalized;

No follow up by the State Hospitals;

Often mentally ill people in crisis are given prescriptions for medication and have no money or insurance to procure the medication;

Lack of appropriate housing for a variety of levels of need.

It is my belief that supportive group living situations could be extremely helpful in filling the housing and support service needs of the homeless mentally ill. The levels of support would vary. Costs for such services would be much less than expensive transitional living centers and mini community based institutions which are just a smaller version of the State hospital.

Most adults want and need independent living. This should be respected and such living opportunities provided. Some degree of independent living should be made available as far as is possible.

Communities need education. The homeless mentally ill are often victimized by police and business people as well as the community in general out of fear and frustration.

Redevelopment and gentrification are eliminating affordable housing units. Communities need to recognize and plan for the needs of the mentally ill when planning or replanning for their community.

A Ministry of the Catholic Diocese of Norwich

Senator GRASSLEY. Thank you.

I want to thank each of you for being so timely in your testimony.

I have quite a few questions. I hope we have time for them.

First of all, I want to apologize to you, Dr. Dave, for not being here to introduce you. I know Senator Hatch did a very good job of that.

Your testimony, I will have a chance to read even though I did not hear it. We appreciate the good job you are doing in Iowa, and particularly taking the time out of your busy schedule to come here.

Even though I may direct questions to a specific person, I would suggest that if any of you have anything to offer to supplement the person who is responding, I would welcome it.

First of all, to you, Dr. Dave, we are pleased to learn that the Community Support Program has been successful in reducing the length of hospital stays. Do you have any further recommendations for the Community Support Program?

Dr. DAVE. Thank you very much, Senator. Thank you for inviting me, and thank you for being here.

I do have some recommendations for the State of Iowa, clearly. As I indicated earlier, and as part of my written testimony, we have moved from providing community support services to 18 counties through 10 mental health centers in 1982, to now, where we have 59 of our 99 counties covered. Service is being provided through 24 of the 32 mental health centers in the State.

I clearly feel that we need to cover the entire State with the projects that clearly are very extremely needed across the State, and are definitely providing the kind of services that the Community Support Program was intended to when it was initiated.

I also feel that there is a scope for bettering the various elements of the community support services which are currently being provided. There is a sufficient number of case management and direct mental health services which are available, but we definitely need additional, supervised and structured living arrangements, for example, partial hospitalization, vocational services—which are not available at present. So we do have a long way to go, and I think the State, Federal and local partnership that was alluded to earlier in today's hearing, needs to be continued further.

Senator GRASSLEY. I would like to ask for your suggestions, because you mentioned the need for innovative approaches to service delivery. Besides those suggestions, I would like to have, as a provider of care, whether or not you have access to the results of the innovative treatment programs funded by the National Institute of Mental Health.

Dr. DAVE. Not directly, but indirectly, yes, sir. Most of the research and the training grants that are available through NIMH—as a previous teacher myself in the field of psychiatry, I think the results of such research trickles down through professional journals all the way to the clinicians who are on the field, providing the treatment. And I think that, as Dr. Frazier and Dr. Talbott mentioned earlier, clearly, there is a need for this kind of research. Without research, we will maintain the status quo, and we need to find answers, such as what ultimately can we do better for the schizophrenic patient; what can we do to prevent the chronicity that such illnesses produce. These answers need to be found. And I think that the research and the training grants provided for NIMH are clearly very helpful.

Senator GRASSLEY. The first part, though, I was asking for your suggestions on innovative approaches to service delivery

Dr. DAVE. Yes, sir. There are several thoughts that I have. Number one, the Community Support Program itself, I think, was a brilliant innovation. It was one of those few programs that did not intend to start a new agency or organization. I think it was intended to utilize the 74 existing services available in the community, tie them together in a proper fashion, in an adequate manner, so that they can be utilized by the patients who need them.

I think that the umbrella agencies that we have in Iowa—the division of mental health, mental retardation, and developmental disabilities—which, under its umbrella agency, has oversight responsibility over not only the State hospitals, but also the mental health centers, is clearly an innovation.

I think that the outpatient commitment laws which are existent in Iowa, are helpful for people who might not be willing to participate in treatment on a voluntary basis and might indeed drop out of treatment, thereby jeopardizing return to the hospital status. I think these are innovations that need to be looked at.

Senator GRASSLEY. Mr Rogers?

Mr. ROGERS. Yes, Senator. I think one of the innovations that I have seen come out of the Community Support Program at the National Institute of Mental Health, that I think has impacts that we will not be able to tell for a long time, but I think they are gonig to be large impacts, and I think it grows out of the sort of "new federalism" in many ways, and the new situation we find in terms of the idea that people can actually become self-sufficient; that giving supports toward self-sufficiency is something that really can work, and that a Community Support Program and small grants have begun to fund local groups and help local groups of mental patients themselves come together in self-help groups, self-help advocacy groups. These are small groups of patients; we run the groups ourselves. We are coming together in a national network of self-help groups. And one of the things we learn is we take the experiences that we have learned in the programs run by Dr. Stein and the other doctors, and we find way to have self-care and continue to self-involve ourselves and keep ourselves from becoming isolated, which is one of the major contributors to regression and going back into the hospital, is becoming isolated, getting lost in the community. And these small groups, these survival groups of former mental patients are growing as a result of the Community Support Program's willingness to include us in their planning, and willingness to bring us into their conferences and aiding us, in such organizations as the Mental Health Association's support.

It is a small movement, and it is a growing movement. In fact, I was out in Iowa, speaking to a group there and we are going to be forming five groups in the State of Iowa very soon. of mental patients, people who have come out of the hospitals, have gone through the programs, and now want to survive in the community and be self-sufficient and truly reach for independence. A lot of this has grown out of the Community Support Program. I was invited, in fact, by the Community Support Program in Iowa to come and speak.

Senator GRASSLEY. Dr. Dave, just a short response as to the extent to which you involve families, and does it seem to help long-term, the involvement of families?

Dr. DAVE. Yes, sir, it definitely does. We, not only at the hospital, but at the mental health centers in northeast Iowa, we have a very strong philosophy of involving the families in the treatment of the patient. I think that the more the family knows about the patient's needs, the more the family can support.

And also, there are occasions when the family itself needs support. And I think the support service that we provide for the families is definitely of utmost importance.

Senator GRASSLEY. One of the earlier witnesses suggested that although there are few chronic mentally ill patients in hospitals, that is where most of the money goes. Is that the same situation in Iowa? Is that where most of the money goes?

Dr. DAVE. Yes and no.

Senator GRASSLEY. Or, maybe you would dispute the previous witness. I am just quoting the previous witness.

Dr. DAVE. I think clearly, nationally, the funding for the State hospitals clearly probably is more than the funding for the community programs. However, I feel as the superintendent of a State psychiatric hospital that there is a need for that kind of service, that we definitely feel, and we have a philosophy at my hospital, that we are the tertiary care center, just like the University of Iowa Hospital provides the expert care when the local community cannot; that there are patients in general medical and surgical practice who indeed need the expertise of the university.

We feel that we are such a hospital. We definitely promote and encourage care at the local level. We encourage admissions and hospitalization at the local general hospital psych units, and yet there are patients who cannot be handled at such facilities, either because of their aggressiveness or because of the level of care and the staffing requirements which are needed, that they need to be hospitalized at facilities such as mine.

So I think that a balance has to be struck between the State hospital setting and the community setting, and I feel that there is need for both.

Senator GRASSLEY. Yes, Dr. Stein.

Dr. STEIN. I do not think there is disagreement about a need for both hospitals and communities, but the data is very, very clear there is a maldistribution of funds. Nationally, 70 percent go to hospitals, 30 percent go to communities. In some of our States, 85 percent go to hospitals, 15 percent go to communities. I think there is a general consensus that there is a maldistribution of funds.

Senator GRASSLEY. I would ask you all from your experience, based on some percentages and figures that Dr. Dave gave, you broke out men, women, a lot of statistics in that way. One of the things that jumped out is the fact of the small percentage of minorities involved. Now, I understand we only have 2 to 2.5 percent of my State that are minorities, but what I need to know is, is that because that is the situation in our State, or would you find that in other States, that there would be a very low percentage of minorities that might signal that minorities tend to have difficult access to the system?

Dr. DAVE. Clearly, I want to respond to the Iowa situation first. Our own data about the community support programs indicate that 97 percent of the population served was white. But then, as you mentioned, Senator, our State does have about 2.5 percent minorities.

Now, so far as the inpatient hospitalization, it is interesting that the four State hospitals in Iowa admitted 93 percent whites, followed by 4 percent blacks, 2 percent Indian, and the rest were Hispanics and others.

Now, although overall, in fiscal year 1983, there was a reduction in the actual numbers of white patients admitted, there were 55 more black patients, 17 more Indian patients, and 5 more Asians admitted during that 1-year period.

And in the Mental Health Institute at Independence, which is closer to the metropolitan centers of Waterloo and Cedar Rapids, we do have a 6 percent admission rate of nonwhites.

So I think that the access to the system is clearly available to minorities, and I do not think that that is a problem in Iowa. Nationally, I am not aware of all the statewide breakdowns of statistics, but an NIMH study which I was reading just prior to coming here indicated that there were 8 percent minorities participating in the available community support programs. So I think that the ratios are pretty much what the general population breakdowns are.

Senator GRASSLEY. I would ask Dr. Stein and Mr. Rogers for a short response, if I could, or if there is any deviation in the States that you might know about.

Mr. ROGERS. I work in Philadelphia, and we have in total in the city population, nearly 50 percent people of color—you do not call them minorities in Philadelphia; when you make up 50 percent of the population, you are not a minority.

The situation there is that we have a real lack and a real crisis in all social services in the city of Philadelphia. We are overwhelmed. And that is where minorities are located, in the inner cities. There are weekends when people who are in severe psychotic crisis that hospital emergency rooms must close down because they have lack of staff available.

So I think for the inner city areas in particular, there is a crisis, a financial crisis and other kind of crisis, that really impact, I think, on the minority population's access to services.

Senator GRASSLEY. But it is not directed to minority population, any sort of—it comes from economic factors.

Mr. ROGERS. Yes; I do not think it is a discrimination necessarily, except that where minorities are located is where we have the highest impact on these kinds of services. So you have minority populations facing very desperate situations.

Dr. STEIN. I think the Community Support Program has done a lot to increase access of minorities to mental health services. Prior to that, when most mental health centers provided primarily outpatient psychotherapy services, those were not the kinds of services that minorities tended to seek. Community support programs were developed primarily for people with severe illnesses, and that cuts across all racial groups, and it has made it more available to those people.

Senator GRASSLEY. This will have to be my last question, and I did have some specific questions directed toward Dr. Stein and Mr. Rogers, so I will probably have to submit those in writing. Before I say for sure, though, that we are going to submit them in writing, I am going to have staff review to make sure that they have not been covered by previous testimony.

Again, directed to you, Dr Dave, in your statement you alluded to the special difficulties caused in the upper Midwest by the farm crisis. And of course, I presume you are implying that the resources, particularly State resources, because of the downturn in the economy of the farm States, is squeezed.

Let me ask you to tell us about stress-related problems in Iowa which are related to the farm crisis—and of course, you probably would realize that I have had a lot of constituents come and talk to me who are very concerned that there are serious negative effects on the cohesion and the stability of the farm family. I would say we have especially had pointed out to us over a long period of time—I do not know whether it can be statistically supported, but at least a perception—a large increase in suicides. Could you proceed?

Dr. DAVE. Yes, Mr. Chairman. I think that there definitely is an impact of the farm crisis. I think that it has shown in an increase in the number of patients served by several mental health centers. There has been a slight increase in the number of admissions at the four State hospitals. And as a matter of fact, one county in southwest Iowa did report a rather dramatic increase in the number of suicides reported in that particular county.

I think that we have seen patients who have presented with anxiety, depression, excessive use of alcohol, marital difficulties, because of farm stress. We have noted even children who, in the recent past, had had the knowledge of security of their family roots, sort of, who have suddenly become anxious, have suddenly turned to acting out behavior, and there has been an increase in the level of anxiety and concern among the children of dislocated farmers.

We in the State of Iowa have tried considerably to alleviate this stress, the mental health component of that. We have started several farm support groups in several centers. The department of human services' rural crisis hotline has been in effect for several months; it is manned 24 hours, around-the-clock, with experts available at the other end to counsel distressed farmers.

We have tried to provide retraining programs for dislocated farmers. Just last week, I was at a center where I saw a 55-year-old man who is going to an accounting class at Kirkwood Community College, and he is extremely anxious, not because he is going to college but because he said, as he was telling me, "My brain is not as good as it was when I was 18, or 19. I have these 18-, 19-, and 20-year-olds sitting next to me, who grasp promptly what the teacher says, and I just cannot." He is feeling anxious, he sweats, his heart beats faster, and that is his concern.

So there are indeed problems that are being shown symptomatically, and we do have to face them in our State particularly and in other rural States.

Senator GRASSLEY. Because of the vote, I am going to thank you all for coming. You are the last panel, so the meeting will stand adjourned at this point.

Thank you.

Mr. ROGERS. Thank you, Senator.

Dr. STEIN. Thank you.

Dr. DAVE. Thank you, Senator.

[Additional material supplied for the record follows:]

IAPRS
INTERNATIONAL ASSOCIATION OF PSYCHOSOCIAL REHABILITATION SERVICES
P O Box 278 McLean, Virginia 22101 Ph 703-237-9385

TESTIMONY

ON

BARRIERS TO HEALTH CARE / CHRONICALLY MENTALLY ILL

BEFORE THE

COMMITTEE ON LABOR AND HUMAN RESOURCES

UNITED STATES SENATE

OCTOBER 9, 1985

BY

VERA MELLEN, PRESIDENT,

INTERNATIONAL ASSOCIATION OF PSYCHOSOCIAL REHABILITATION SERVICES

WHO WE ARE AND WHO WE REPRESENT

This statement is being presented by Vera Mellen, President of the International Association of Psychosocial Services (IAPSRS), and Executive Director, The Social Center for Psychiatric Rehabilitation, Fairfax, Virginia.

IAPSRS is composed of agencies and individual members, the vast majority in the United States, as well as statewide and regional chapters. The purposes of the Association are to help advance the role, scope, and quality of services designed to facilitate the community readjustment of the psychiatrically disabled.

More specifically, IAPSRS undertakes to establish improved communications among all levels of personnel active in this field, through annual conferences, special workshops and meetings, newsletters, a journal, and other channels. It assists agencies and practitioners regarding issues of program development, evaluation and follow-up procedures, staff utilization and training, management and administration, and improved understanding of the needs confronting the psychiatrically disabled. Finally, it undertakes to serve as spokesman and advocate for the cause of community-oriented psychosocial rehabilitation and to provide all necessary assistance in assuring that the best interests of all concerned sectors--providers of services and consumers alike--are effectively maintained.

WHAT IS PSYCHOSOCIAL REHABILITATION?

Briefly defined, psychosocial rehabilitation is comprised of goal-oriented programs for mentally ill persons which provide experiences to improve their abilities to function in the community. The philosophy underlying such a program emphasizes common sense and practical needs, and usually includes vocational and personal adjustment services geared toward the prevention of unnecessary hospitalization. The psychosocial rehabilitation setting is purposefully informal to reduce the psychological distance between staff and members (or clients) as active participants in program planning. Members are continually encouraged to assume productive citizenship roles within the psychosocial rehabilitation facility and in the broader community, which is viewed as an integral part of the total psychosocial rehabilitation setting.

HOW MANY SUCH PROGRAMS ARE AVAILABLE?

A partial network of community-based rehabilitation programs for the seriously and chronically mentally ill population has developed over the last three decades, and that development has somewhat accelerated in recent years, as many treatment-oriented agencies have begun to include psychosocial rehabilitation services in their programs. At the recommendation of the National Institute of Mental Health (NIMH) the U.S. Dept. of Health and Human Services contracted with IAPSRS to identify all such programs in the United States. The resulting first *National Directory of Organizations Providing Psychosocial Rehabilitation and related Community Support Services in the United States* has been published recently. It lists (and briefly describes) 985 local agencies describing themselves as providing such services.

It is generally recognized that there are between 1.7 million and 2.4 million seriously and chronically mentally ill adults in the United States.

BARRIERS TO EFFECTIVE COMMUNITY-BASED REHABILITATIVE CARE

A major problem for making adequate community services available to long term mentally ill persons is the hard fact of the barriers and disincentives against such services which exist in many federal programs. Such barriers and disincentives have been investigated and reported to Congress by the Comptroller General (*Returning the Mentally Disabled to the Community: Government Needs to Do More*, 1977), by the President's Commission on Mental Health in 1978, and reported to the Secretary of Health and Human Services by the Department's Steering Committee on the Chronically Mentally Ill, in the monumental *Toward a National Plan for the Chronically Mentally Ill*, published in 1980. The Comptroller General stated in 1977 that "Although the States are primarily responsibile for the care and treatment of the mentally disabled, many of these problems are attributable to (1) Federal programs which provide financial incentives that inhibit the appropriate placement of the mentally disabled and (2) the lack of leadership and action by many Federal agencies whose programs do, could or should affect community placement."

Also in 1977, the HEW Task Force on Deinstitutionalization of the Mentally Disabled reported "difficulty in financing community-based care due to institutional care biases imbedded in the big-money Federal programs--Medicaid, Medicare, and SSI; these biases impede development of appropriate facilities and services in the community...." (quoted in *National Plan*, page 1-7).

These barriers and disincentives have the cumulative effect of denying exactly the kinds of community supports for health that both experience and research have proved to be effective and necessary for sucessful reintegration of chronically mentally ill individuals in the community. Such community supports must include adequate housing, income, psychosocial (including vocational) rehabilitation, general health care and mental health treatment, in a supportive and accepting community. Federal programs dealing with these issues generally are either insufficiently oriented to the needs of persons with mental illness or actively discriminate against them. This fact makes it extremely difficult for States and local communities to provide the full array of community services needed.

The Congress took a major step to remove one barrier to the opportunity for many mentally disabled to live comfortably or "make it", in the community (the goal of community-based health and rehabilitation services) by passing the Social Security Disability Benefits Reform Act of 1984 (Public Law 98-460). The Act is intended to help redress and prevent the cruel and destructive denial of disability benefits, often with loss of Medicaid eligibility, to thousands of severely mentally disabled individuals.

EFFECTIVE PROGRAMS IN SUPPORT OF CHRONICALLY MENTALLY ILL PEOPLE

Members of Congress are to be thanked and congratulated for continuing a number of important programs having direct impact on this population, among them most especially the excellent research, training, and service-related programs of the National Institute of Mental Health (NIMH). NIMH Director Dr. Shervert Frazier will undoubtedly describe these activities and their significance in his testimony before the Committee. I now wish to comment briefly on a small, but for long-term mentally ill persons, a vital part of the NIMH, that is, the Community Service Systems Branch of the Division of Education and Service Systems Liaison. Through its Community Support Program (CSP), this small NIMH Branch, initiated in 1977 and currently funded at $10.5 million, works with states and localities to improve opportunities and services for adults with chronic mental illness (such as schizophrenia and manic depressive illness). The Branch activities related to mentally ill adults include CSP grants, technical assistance interagency collaboration, and evaluation services. CSP awards and grants have gone to every State, and though the amount of funding is small, results have been very significant. For only one example, in almost every State the chronically mentally ill have been made the priority population for mental health services. The CSP has contributed in a major way to increasing the availability and accessibility of community-based rehabilitation and support services to this population Following is a summary of CSP accomplishments in just one State--the State of Utah.

Utah's CSP project was funded effective August 1, 1982. As of March, 1985, the following specific outcomes were identified: At the grant's inception, day treatment services were provided only in the six large mental health centers. At this time, day treatment is carried on in all of the catchment areas across the state. In 1982. psychosocial rehabilitation programming was available in only one center. As of now, eight centers provide psychosocial rehabilitation.

In 1982, family support groups were active in two catchment areas. Today family support groups exist in six of the catchment areas. At this time, a statewide Utah Alliance for the Mentally Ill (UAMI) has seven chapters in urban and rural areas of the state and all are affiliated with the National Alliance for the Mentally Ill (NAMI). All UAMI chapters are now taking an active role in advocacy and have made presentations to individual legislators and legislative subcommittees. UAMI has elected three representatives to serve on the CSP Steering Committee.

In 1982, consumer self-help groups existed in two catchment areas. Today, these groups have expanded to 11 catchment areas. Five consumer conferences have been held across the state, attended by roughly 100 consumers on each occasion. A statewide consumer council has been formed. This council meets to discuss such issues as evaluation of mental health services, development of the consumer self-help movement, advocacy and public education. The consumer council has elected three representatives to serve on the CSP Steering Committee.

Residential beds in both urban and rural areas of the state have increased roughly to 125% since 1982. The entire increase cannot be credited to CSP initiatives alone; however, program managers across the state feel that CSP technical assistance directly influenced a 25% increase in the number of residential beds available statewide for the mentally ill.

In 1983 a Utah CSP Media Development Committee was formed. Prior to the CSP project, no formal media group existed. The Media Committee publishes a quarterly newsletter, sponsors media and mental health workshops to educate mental health professionals and advocates in the use of media for public education. The Media Committee developed a resource file which was distributed to media representatives, legislators, county commissioners, city police, and county sheriffs across the state. The resource file is updated quarterly with new material.

The Utah CSP Project maintains a video library, provides speakers for special events, and has planned and conducted numerous workshops and conferences directed toward the treatment of the chronically mentally ill.

The Utah program is just one of many CSP projects of which IAPSRS is aware. Together, these State-operated programs are making a substantial contribution to the development of effective and accessible systems of health care for chronically mentally ill individuals.

HOMELESSNESS AND MENTAL ILLNESS

Because homeless mentally ill adults are a sizable and particularly vulnerable portion of the total homeless population, IAPSRS has participated in the creation of the National Leadership Coalition on Mentally Ill Persons Who Are Homeless. The National Mental Health Association is reporting to this Committee in detail the legislative recommendations from the Coalition. For that reason IAPSRS at this time will simply state our full support and endorsement of these legislative recommendations.

KENNEDY MENTAL HEALTH PROPOSALS

We have seen drafts of the mental health bill being developed by Senator Kennedy and his staff, and are pleased at the extent to which the drafts address some of the most serious barriers to effective community-based care for chronically mentally ill individuals. We are convinced, on the basis of the drafts we have seen, that enactment of such a bill into law would have constructive impact on a number of the barriers outlined above. For example, Medicaid would be made consideraly more relevant and effective by the provision of case management services for chronically mentally ill Medicaid-eligible individuals. In the experience of those of us who are involved in psychosocial rehabilitation services, case management is an indispensable component of a comprehensive community support program and is well described in the draft legislation. Passage of such a bill as drafted would require Medicaid State plans to provide for community and home-based care for Medicaid-eligible chronically mentally ill persons, and further, would relate Medicaid reimbursement for nursing home care to the meeting of standards for appropriate care for such individuals. The bill makes other needed changes in both Medicaid and Medicare, all well designed to remove certain widely recognized barriers to quality community-based health care for long-term mentally disabled persons. It also makes several urgently needed changes in the Supplemental Security Income (SSI) program of the Social Security Administration, including the establishment of SSI presumptive disability for six months for individuals certified by the State Mental Health Agency as chronically mentally ill and about to be discharged from an insitution, at imminent risk of institutionalization, or homeless and willing to participate in a plan of care. Other important provisions of the legislation include needed support for comprehensive mental health planning by the States, establishing national standards for a community-based care system for the chronically mentally ill, and making needed changes to permit Federal housing programs to be more appropriately responsive to the housing needs of this population.

IAPSRS WISHES TO BE OF ASSISTANCE TO THE COMMITTEE

On behalf of the members of the International Association of Psychosocial Rehabilitation Services, I thank the chairman and members of the Committee on Labor and Human Resources for this opportunity to present our views on the subject of the Committee hearing. We are eager to be of every possible assistance to the Committee in order to help make quality health care more accessible to Americans suffering from serious and chronic mental illness.

American
Psychological
Association

TESTIMONY OF

Leonard D. Goodstein, Ph D

Executive Officer

The American Psychological Association

on behalf of

THE AMERICAN PSYCHOLOGICAL ASSOCIATION

before the

UNITED STATES SENATE

COMMITTEE ON LABOR AND HUMAN RESOURCES

on the subject of

BARRIERS TO HEALTH CARE: MENTAL HEALTH

Services for the Chronically Mentally Disabled

October 9, 1985

Honorable Orrin Hatch, Chair

1200 Seventeenth St. N.W.
Washington, D.C. 20036
(202) 955 7600

Mr. Chairman and Members of the Committee, I am Dr. Leonard D. Goodstein, Executive Officer of the American Psychological Association. I am representing the 76,000 members of the Association and thank you for the opportunity to comment on the issue of barriers to mental health care for the chronically mentally disabled. We are pleased to learn of the Committee's interest in examining the accessibility of community mental health services to special populations. In our testimony, we will focus specifically on existing Federal programs for the chronically mentally disabled, the unique mental health needs of special populations, a system of care model for service delivery, and the impact of financing structures on the delivery of mental health services.

Psychologists have always played a significant role in responding to the needs of the chronically mentally disabled. In addition to providing essential services to the chronically mentally disabled, psychologists administer twenty state mental health service programs as well as conduct pioneering research and program development efforts. It should be noted that psychologists represent the majority of doctoral level staff employed in the over 2,000 community mental health centers across the country; the typical center staff is mainly comprised of masters level psychologists and social workers. Psychological services provided in community settings include diagnostic assessment, psychotherapy, clinical consultation, crisis intervention, community referral, and prevention and outreach services. In the areas of research and program development, psychologists are examining the causes of severe mental disability and are actively involved in designing and evaluating new approaches to traditional hospital-based care and drug therapy, which include milieu therapy and social learning therapy, for the treatment of chronically mentally disabled persons.

Federal Support for Services for the Chronically Mentally Disabled

A careful analysis of barriers to mental health care for the chronically mentally disabled requires some attention to the evolving relationship between Federal, state, and local levels of government. Prior to the enactment of Federal legislation authorizing the establishment of community mental health centers and the Medicare/Medicaid programs, mental health care for the chronically mentally disabled was primarily a state responsibility handled largely through placement in state institutions. However, Federal, state, and local governments have been unable, for a variety of reasons, to provide the continuity of care required to assimilate the chronically mentally disabled into the community.

The 1963 Community Mental Health Centers Act created a nationwide network of community mental health centers (CMHCs) and constituted the first step toward promoting a community-based system of outpatient care as an alternative to institutionalization. Despite the relative success of the CMHCs, in the early 1970s, Congress responded to evidence showing that traditionally unserved groups such as the poor, the elderly, and the chronically mentally disabled remained inadequately served. As a result, the number of "essential services" to be provided by the centers was increased, but sufficient funding did not accompany the changes. However, the creation of the CMHCs served to establish a relationship between the Federal and local governments in the delivery of mental health services.

The enactment of the Mental Health Systems Act in 1980 attempted to add the state to this partnership, by giving states the option of contracting to be the sole provider of mental health services. In recognition of the unmet mental health needs of certain populations, the Act added new provisions to encourage the development of outreach and service programs for the elderly, the chronically mentally disabled, severely disturbed youth, and other underserved populations. However, the funding level was far below what would be required to provide comprehensive services for these populations.

Alcohol and Drug Abuse and Mental Health Services Block Grant. A major shift away from Federal support for mental health programs for special populations occurred in 1981 with the creation of the Alcohol and Drug Abuse and Mental Health Services (ADM) block grant and the repeal of the Mental Health Systems Act. The Federal role in providing a nationwide network of community mental health centers [illegible] thereby reduced and the role of the individual states increased

The mental health share of the ADM block grant is distributed primarily to community mental health centers and is intended to provide states with greater flexibility; yet the chronically mentally disabled and the elderly are designated as service priorities. The block grant serves to reduce government bureaucracy, thus giving states the opportunity to pool resources to provide a more comprehensive range of health, mental health, and social services. However, state savings from the block grant approach are not sufficient to compensate for the reduced levels of Federal funding, a situation which has been compounded by inflation.

In addition to the ADM block grant, other Federal programs must be considered in an evaluation of current barriers to the provision of mental health care for the chronically mentally disabled. These programs include the Community Support Program and the Clinical Training Program which are both administered by the National Institute of Mental Health (NIMH).

Community Support Program. The Community Support Program (CSP) attempts to eliminate barriers to mental health care by providing grants to states and private nonprofit agencies to establish more effective ways to provide community mental health services to the chronically mentally disabled and other seriously underserved populations, such as children, the homeless, and the elderly. The 37 participating states and the Federal government agree that this effort has been highly successful. We believe that the current CSP models may be useful in determining some of the more effective ways to reduce barriers to mental health care at the state level.

Clinical Training Program. This Program is the major source of funding for training in the four core mental health professions--psychology, psychiatry, social work and psychiatric nursing. The program prepares these professionals to meet the nation's mental health needs by requiring that students receiving a stipend spend one year working in a designated shortage area for each year of Federal support. Funding for this program has declined drastically over the past decade, but has stabilized in the past three years at about $20 million. However, the Program appears to be in jeopardy this year, since the House Appropriations Committee recommended a funding level of only $8 million, as contrasted with the Senate Appropriations Committee figure of $24 million. Continuation of adequate funding for the Clinical Training Program is a prerequisite for ensuring adequate numbers of mental health professionals to work with the chronically mentally disabled and other special populations.

Special Populations

There are many factors which must be taken into account in a discussion of the availability and quality of community services for the chronically mentally disabled. First, the post-war baby boom generation has entered the age range at highest risk for mental disorders (i.e., 25 to 45 years) and may be expected to place an undue burden upon existing community mental health services. Second, we have not been able to bring large numbers of the chronically mentally disabled of the growing homeless population into the existing mental health system. Third, we also know that there are unique mental health needs among those chronically mentally disabled who are children, elderly women, or the homeless, for example.

Children and Adolescents. According to recent studies, an estimated three million children and adolescents in the United States suffer from severe mental disability. Two-thirds of these children are not receiving the services they need and many others are receiving inappropriate or excessively restrictive care. Among children with multiple problems or without supportive home environments, even fewer receive care.

In response to this situation, Congress targeted 10% of the mental health share of the $490 million appropriation for the ADM block grant in FY 85 for mental health services for severely disturbed children and adolescents and for unserved areas or underserved populations. The previous year, Congress had earmarked $1.5 million of CSP funds to establish a new initiative to improve mental health service delivery systems for severely emotionally disturbed children and adolescents. The goal of the Child and Adolescent Service System Program (CASSP) is to assist States in developing a comprehensive and coordinated system of care for mentally disturbed children and youth in communities

The response to the initial NIMH program announcement for CASSP was overwhelming: 44 states and territories submitted applications to compete for the $1.5 million. However, funds were only available to award 10 grants. With the increased FY 85 appropriation of $3.9 million, NIMH was able to fund an additional 10 or 11 States and territories.

For the past two years, the Administration has proposed to eliminate CSP with the rationale that the successful CSP demonstration projects could be implemented through the ADM block grant. We believe there is still a strong need at the State level for Federal leadership in designing programs like CASSP which serve as effective models for responding to the needs of chronically mentally disabled adults.

Women. The mental health needs of women was the focus of a joint project undertaken two years ago by the American Psychological Association, the Women and Health Roundtable, and the Federation of Organizations for Professional Women. The report entitled "A National Agenda to Address Women's Mental Health Needs" suggests that chronically mentally disabled women have different and more extensive problems than men. For example, chronically mentally disabled women are more likely to be sexually active than men. In the absence of birth control information, this factor may result in substantial numbers of unwanted pregnancies. These women may also be particularly vulnerable to sexual assault. The report also noted that for the substantial number of these women who have children, life stress may be compounded by the fact that their children are also at higher risk for emotional disturbance. Another finding that has implications for devising systems of care is that providers often assume that a return to the family is the best outcome for mentally disabled women, without considering that the family structure itself may have significantly contributed to the women's problems.

For all of the chronically mentally disabled, but especially for women, barriers to care include a range of economic and social problems. One study of chronic mental patients found the average monthly income of men to be $220, as compared to $36 for women. Additionally, referrals to vocational training programs are less frequent for women, and rehabilitation programs have been found to prepare men to become economically productive while reinforcing traditional expectations of "learned helplessness" for women. We also know that in some areas of the country, the scarcity of shelter space for women greater than for men, and intake policies and regulations for women's shelters are often more restrictive.

Elderly. We are also concerned about the availability of mental health services to the elderly chronically mentally disabled living in the community. While a recent NIMH study found that 11 of 15 states have designated the chronically mentally disabled as a priority service population, it is doubtful that services are reaching the elderly of this population.

According to a nationwide survey of CMHCs conducted this year by the Action Committee to Implement the Mental Health Recommendations of the 1981 White House Conference on Aging, in conjunction with the American Psychological Association and the National Council of Community Mental Health Centers, the elderly were found to be severely underserved--receiving less than half the level of services that would be expected based on their percentage of the population. This survey is a two-year followup of a similar one conducted in 1983 to determine the amount of mental health services being delivered to older adults in the community and the impact of the change in Federal financial support from the categorical approach to the block grant method on such services. The following is a summary of the survey findings:

- o The elderly are a severely underserved group, receiving only 6% of CMHC services (the aged comprise 12.6% of the national population).
- o There has been a decrease in the number of special aging programs delivered through CMHCs.
- o There has been a significant decrease in Federal support for mental health care, which has been only partly compensated for by state and private sources of support.
- o Clinical services have been reduced.
- o The adverse effects of the block grant program are being felt nationwide.

The reduction in Federal support and the change to the block grant method of funding has in many states shifted the focus for service to the chronically mentally disabled, but not necessarily to the elderly of this population. The Action Committee survey cited the reduction in Federal funding and staff reluctance to work with the chronically mentally disabled elderly as the major impediments to the delivery of mental health services to this population. CMHCs identified the following as negative effects of the decrease in Federal support: 1) reduction in the number of clinical staff; 2) reduction in outreach efforts to inform the aged of available services, 3) fewer sustained cooperative efforts with aging services agencies; and 4) reduction in transportation services, which in rural areas has made it more difficult for the aged to obtain mental health services.

<u>Homeless</u>. Though not all of the homeless population is chronically mentally disabled, we are concerened about the significant numbers who are. Of the homeless population, it is believed that a greater proportion of women than men have serious psychopathology, which is often combined with substance abuse. The chronically mentally disabled homeless, as well as others with chronic disabilities, require much more than long-term mental health care.

Basic needs such as shelter, food, income maintenance, and legal services must be tied to health and mental health care. All of the above have implications for appropriate case management and the need for systematic outreach to the underserved. And, we still need mechanisms for increasing community awareness and acceptance of the chronically mentally disabled homeless to ensure available housing in locations that are safe and convenient to gain access to services

The American Psychological Association in conjunction with 16 other national organizations supports the amendments to H.R. 1, the Housing Reauthorization bill, that attempts to redress some of the urgent services and transitional housing problems that face the chronically mentally disabled and homeless individuals. The coalition also advocates that Congress adopt a range of legislative proposals to meet the needs of the homeless population. These proposals include:

- the establishment of a category of presumptive disability in the Social Security Administration (SSA) for seriously and chronically mentally disabled persons being discharged from state institutions to ensure that Social Security benefits are payable upon discharge, and mandating outreach by SSA staff to potential recipients in emergency shelters;
- the extension of SSI eligibility for shelter residents up to 12 months;
- the funding of state planning initiatives to identify and plan for needed services for homeless chronically mentally disabled individuals;
- the initiation of demonstration projects through NIMH to serve homeless mentally disabled persons; and
- the expansion of research into the causes of homelessness, the demographics of this population, and their service needs.

The coalition looks forward to discussing these and other possible reforms with the members of the Committee in upcoming weeks.

The "System of Care" Model for Service Delivery

The chronically mentally disabled, whether children or adults, require a range of age-appropriate mental health services at varying levels of intensity. The primary goal of the service system is to provide appropriate services to each client in the least restrictive environment. The term "appropriate services" refers to those services that are essential to enable the individual to progress in the development of appropriate behavior and independent living skills, and to move from more restrictive to less restrictive settings.

The most central component of this model is the availability of a range of residential and non eidential mental health services. Residential services include supervised apartment or monitored independent living, therapeutic homes, residential treatment, or inpatient care. Nonresidential services include outpatient or day treatment, diagnostic services, crisis intervention, home-based care, support and respite services for families, consultation and education, life skills training (including pre-vocational and vocational preparation) and case management.

The other key components of an effective mental health service system include: (1) linkages among the various components within the system; (2) access to a full continuum of care; (3) flexibility in funding and decision-making to allow the movement of individuals through the system as their needs change; and (4) responsive management structures that allow for shifts in funds and staff. Moreover, since the multiple needs of the chronically mentally disabled population invariably require the intervention of other agencies and systems, it is critical that services be well coordinated to reduce fragmentation and the less frequent duplication of services.

The American Psychological Association encourages the Committee to explore how the systems of care model can be applied to the chronically mentally disabled We are particularly concerned about the influence of Federal financing structures such as Medicare and Medicaid (which focus heavily on hospital care and minimally provide for appropriate outpatient care) on the development of systems of care.

Financing Structures as an Impediment to Services

Public and Private Financing and Community Care. The financing mechanisms for mental health exert a significant influence on the extent to which services are available to persons who need them. The various Federal and Federal-state mental health initiatives of the past several decades to provide services for the chronically mentally disabled have suffered as a function of the growing costs of care coupled with decreased Federal support. The public and private financing mechanisms for service delivery to this population are further impediments to levels and appropriateness of care.

Care for the treatment of mental and nervous disorders was historically left to the family. Today, private health insurance and state and Federally funded programs drive the health care system. We have moved away from institutionalization to community-based care in practice, but reimbursement mechanisms continue to favor hospitalization. This disparity is a significant barrier to care.

Both public and private insurance plans limit coverage for mental health care. With respect to Medicare, the focus is on acute hospital-based care, yet includes an inpatient benefit for mental and nervous disorders of only 190 days per lifetime. Recent estimates from the Health Care Financing Administration suggest that less than 1% of the Medicare beneficiaries exceed the current lifetime limit and that approximately 2% would exceed a 60 day per year limit. Despite these small percentages, this limit is unacceptable, since there are some persons such as the chronically mentally disabled whose needs will exceed the 60 day limit. Another unfortunate consequence of this policy is that since the limit applies only to psychiatric hospitals, it ignores the other settings, such as skilled nursing facilities (SNFs) and intermediate care facilities (ICFs), which treat considerable numbers of the aged and mentally disabled. The limited outpatient benefit of $500.00 per year with a 50/50 copayment is likewise a barrier to care. Typically, this provides for 10 visits to a private practitioner's office or to a clinic. This level of coverage for the chronically mentally disabled is patently inadequate.

In addition to outright limits on services or reimbursements, both Medicare and Medicaid have severe limits on both locus of care and on professional providers. For instance, nearly all states construe the Federal requirement that Medicaid services be "medically necessary" as meaning that they must be provided under the authority and supervision of physicians, rather than independently by licensed nonphysician mental health professionals (i.e., psychologists, social workers, and psychiatric nurses).

Unfortunately, the private sector has followed the model provided by the Federal government. Private insurance coverage for the treatment of mental and nervous disorders is, on the average, just as limited as in public plans. Copayments are generally 50/50 instead of the 80/20 commonly found for other health care. And without exception, there are use or dollar limits on reimbursement. A recent study of 300 private sector plans reported that over 30% of the plans had benefit levels for both the inpatient and outpatient treatment of mental disorders at a lower level than benefits for other types of health care. Nearly 60% of the plans had similar inpatient benefit levels for the treatment of health and mental health conditions, however, these plans offered less coverage for the outpatient treatment of mental health conditions as compared to other health conditions.

Public Financing and Residential Care. The consequences of the Medicare limitations on type and place of care promote the costly and inappropriate use of alternative services and facilities. Also, Medicare inappropriately defers to the Medicaid program for certain long-term care needs of the older population, including those with chronic mental disabilities. In this regard, Medicare recognizes only hospitals as institutional providers for mental health care and denies payment to skilled nursing facilities (SNFs) for this care. Thus, this method of financing creates a significant barrier for beneficiaries who are in nursing homes rather than hospitals.

The long and debilitating course of many chronic diseases, which often includes certain mental health problems, leads to the eventual placement of many elderly patients in nursing homes--intermediate care facilities (ICFS) and skilled nursing facilities (SNFs). Medicare coverage for nursing homes is restricted to the SNF setting with many benefit limitations. When the criteria are met, a total of 100 days of nursing home reimbursement is provided; $50 per day co-payment is required between the 21st and the 100th day. After these benefits are exhausted, the patient must either make personal payments (which account for 44% of all nursing home payments), rely on private long-term care insurance (less than 1% of all nursing home payments are from private health insurance sources), be discharged to the care of family or friends, or, if Medicaid coverage is available, "spend down" to meet Medicaid criteria. The extended course of many chronic conditions, including mental disorders, experienced by the elderly increases the likelihood that patients will exhaust their personal resources and become dependent on state Medicaid programs. At least one-half of Medicaid nursing home recipients were not initially poor upon entering the institutional setting, but had to "spend down" to meet state Medicaid eligibility levels. Medicaid's failure to address the long-term care needs of our nation's elderly will continue to "pauperize" patients with chronic disorders.

Intermediate Care Facilities (ICFs) are a more typical nursing home setting for the majority of elderly persons with chronic conditions requiring long-term care. Although it is not covered by Medicare, most states have opted to offer some type of ICF reimbursemernt through their Medicaid programs--despite the lack of a Federal mandate. Medicaid, by default, provides payment for some of the long-term care services neglected by the Medicare program. Once placement is located in an ICF, an elderly resident with a mental disorder is very likely to be at risk for receiving inappropriate treatment. This phenomenon results from Federal policy which discourages treatment for mental diagnosis by denying reimbursement to facilities classified as institutions for mental diseases (IMD).

The Medicaid statute expressly forbids reimbursement for "care or services for any individual who has not attained 65 years of age and who is a tient in an institution for mental disease (IMD)." Current Medicaid "Guidelines" define an IMD as a facility with a disproportionate share of its patients (i.e., over 50%) with mental disorders. Once designated as an IMD, Medicaid denies reimbursement for residents between the ages of 21 and 65. As a consequence, many nursing home administrators are reluctant to admit residents of any age with mental disorders--or mislabel these residents with physical diagnoses--so as not to characterize their facility as one caring for the mentally ill. As a result, only around 5% of nursing homes residents with diagnoses of mental disorders receive any mental health care.

Medicaid is the largest single source of financing for nursing home care, representing over 40% of all nursing home payments (a total of $13.2 billion in FY 1982). It has been estimated that as many as one-half of the nation's nursing home residents have mental disorders; the care of these residents accounts for almost $16 billion per year.

Another barrier to appropriate mental health treatment for nursing home residents is that neither Federal certification procedures for Medicare/Medicaid nor state licensure laws require that nursing homes provide mental health care when it is indicated. The Medicaid program should establish standards for appropriate care and treatment of the chronically mentally disabled elderly in nursing homes. Medicaid should also mandate mental health care to residents with mental diagnoses for those participating facilities. Further, the Medicare statute should require the certification of SNFs to provide inpatient mental health services so residents with mental disorders could receive direct care.

Thank you for the opportunity to testify on behalf of the American Psychological Association on the subject of community services for the chronically mentally disabled. If we can be of any further assistance to the Committee, please call upon us.

Senator GRASSLEY. The hearing is now adjourned.

[Whereupon, at 11:43 a.m., the committee was adjourned.]

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