Vancouver, 8/25-26/77

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This, from a mother in San Francisco, who is the conservator of a mentally ill son:

> My son is a college graduate. He became ill when he was 28. He has been in mental hospitals. At the present time he is in a locked facility. The drugs he was given just made him worse. His ego is at zero level.
>
> After a while, he would no longer look for even a simple job. The minute he would say he had been in a mental hospital, he was denied the opportunity to even fill out an application. So he lost all hope. Private enterprise will not give jobs to people who have been mentally ill.
>
> He could have worked, and it would have done more to build back his self-confidence than any drug, than anything I or anyone else could ever do for him.
>
> I would do away with 90 per cent of the services and concentrate of places for the mentally ill people to live, where there is something to do all day besides lie down on a bare, cold room with minimum supervision and drugs. That way, they can only stay sick and get sicker.
>
> A wasted education, a wasted life. An uncaring society, institutions which are not humane, and most importantly here, I think, the stigma of mental illness which stood in the way of gainful employment -- at any level -- which might have restored a young man's self-confidence and will to live.

In Nashville, a representative from the Interagency Council on Migrant Services from Newport News, Virginia -- we had very wide geographic attendance at these hearings, by the way -- told this story:

> A woman from a migrant camp, apparently suffering from amnesia or some other kind of disorientation, was observed by a nun who was a social worker as being in need of professional help.

The woman did not know her own name, where she came from or where she was. The following day our staff went to the migrant camp to provide whatever services we could, including transportation to the state hospital. We were brusquely informed by the crew leader that no such woman existed, that the camp would not tolerate crazy people, and we were ordered to leave.

Several days later, the body of the woman was identified by the same nun who had observed her originally. The woman had been killed by a hit-and-run driver. Her true identity is unsolved, and her body rests in a pauper's graveyard.

In this tragic case, we see stigma at its most destructive. We know that among poor, un-educated people there is greater superstition and fear than there is among the more advantaged elements of our society; still, we can see the roots of our own fear and prejudice in such a situation. And we are all the more challenged to do battle with and to banish the stigma that causes indifference to human life.

As I said earlier, stigma pervades many levels of society. In Tucson, we were told of irresponsible bureaucratic practices which have resulted in fanning the flames of already exisiting stigma. The head of the National Association of Social Workers informed us that there is, in many communities, good reason for negative attitudes toward mentally ill persons. Public officials, it seems, have been known to encourage hasty, unplanned discharge practices in local mental institutions in order to cut costs and rid themselves of the traditional responsibility of care for the mentally ill. This is called "dumping" -- mentally diabled persons are literally dumped into instant ghettos, and, unable to care for themselves, fall prey to exploitation from the outside community. Conditions in these ghettoes

In this tragic case, we see the fear of mental illness at its most destructive. In some cultural groups, especially among the poor, there is a fierce pride that goes hand in hand with suspicion of deviant behavior which is in turn overlaid by resentment of outside interference. We know that, we understand that, accept that, but it is a reminder of the difficult and sensitive job we face in trying to rid all segments of society of unnecessary and counter-productive negative attitudes about mental illness so that proper treatment and care can be readily forthcoming. It will be a great day when we learn how to reach over these barriers and an even greater day when these barriers disappear altogether.

An Asian-American psychiatrist told us at the San Francisco hearing of the prevalent attitude toward mental illness among Asians: He said that Asians reject the idea of having a mentally ill member of the family because of feelings of fear, rejections and ridicule. Among the Japanese, for example, this pychiatrist pointed out that to have a mentally ill family member it known that there was a member of the family in great emotional difficulty woudl be to stain the family honor, This blot on the family name, he said, would make it difficult for any other member of the family to obtain good jobs, to marry well, or to get on socially. This attitude is a powerful deterrent For all of these reasons, and because traditionally Asian families want to solve most problems within the setting of the family, there is more than average reluctance to seek mental health services. Indeed, this psychiatrist pointed out that Asian families tend to care for psychotics at home, postponing use of mental health services until an urgent situation arises.

We all agree that cultural traditions must be respected, and as your great founder and former President, Margaret Mead, has so often emphacized, we cannot rigidly impose the standards of Euro-American treatment of psychiatric

We must tailor them
and social problems on other cultures. But as Dr. Mead has also said, we do share a "central mission" to understand the things which bind people of different creeds and cultures together, the human conditions and experiences that are common to all socities. There are, after all, universal themes of death, separation, loss, old age, the ravages of war, economic hardships, and so forth, that are experienced with the same degree of pain by all people.

Dr. Mead has said that if a society selects for first consideration the most vulnerable among them, then the whole culture is humanized. I think that's what we all want, what we are all striving for.

As we do so, we must always think in terms of tailoring mental health services to the special needs of ethnic and racial minorities, and of the poor. At the same time, we must acknowledge our own mistakes, our own deepest and perhaps unrealized prejudices. Because they do exist, and they have been a deterent to proper treatment and care.

In San Francisco, Kelsey Kenfield, a former patient, told me: "Mrs. Carter, at the risk of offending many professionals in this room, I have run into as much prejudice and fear in therapists as I have in others who know of my history."

Another former patient concluded, "Many members of the mental health profession are so condescending to their clients that it is impossible to even talk to them."

Stigma, it seems, is where you find it, and apparently, it is a real or pootential factor almost anywhere in society, including among those places and people who deliver the mental health services.

It is interesting, and perhaps very instructive, to learn what people do as an alternative to seeking professional help, to visiting a mental health clinic, to entering into psychotherapy, to accepting hospitalization. During our public hearings, several people -- ~~some~~ health professionals, some lay ~~people~~ persons volunteers, ~~some~~ former patients -- pointed out that it is quite common for persons in emotional trouble to go to a minister, priest or rabbi, or to friends and neighbors, ~~in~~ for help. Some may even seek out a policeman. Quite apart from trying to avoid the well-publicized cost of traditional psychotherapy, they take this route to avoid the stigma of visiting a mental health professional.

Mrs. Lois McLatchie, a former mental patient in Philadelphia, told us: "Studies have indicated that the majority of persons do not go to professionals when they are beseiged with problems. They go to clergymen, family, friends, neighbors. Going to such a helper does not carry the same stigma as going to a professional."

In a recent survey by the Institute of Social Research at the University of Michigan, most of the people interviewed said that they were afraid to seek professional help for fear of being labeled. (More survey data forthcoming)

Further testimony at the public hearings gave substantial credit to the natural support systems in our society as an alternative to pschotyerapy. Alcoholics and Weight-Watchers were singled out as being free of stigma, just plain free, and most important, successful. They work. Peer-group counseling for adolescents was also cited as perhaps the only way for teenagers to deal with some of their special problems.

Of course these natural support systems and peer intervention groups do not work for everyone, but is is clear that most people would rather

try these routes than risk the labelling they feel is sure to come from having sought professional help.

Going to a therapist for help with a depression is, or ought to be, no different from going to a doctor for appendicitis or pneumonia. But somehow that message has not gotten across. Shame still prevents many people who need help from getting it -- even though they may know others who have benefitted from professional help. ~~Speaking only for Americans,~~ I would have to say that this reluctance, this fear, also reflects our own cultural heritage. We Americans place great value on self reliance, strength, working out one's own difficulties, not burdening other people with one's pain. And these are good values; I believe in them. But I also believe that no one should feel alone in this world, and that to accept the counsel of those specially trained to help also represents good values. This is a message that all of us, working together, must get across.

Since I have been First Lady, I have received thousands of letters relating to my interest in mental health. At least half of them come from mental health organizations around the country that rely heavily on volunteers to raise funds, distribute information, work with outpatients who are making their re-entrance back into the community, provide transportation to and from clinics for elderly shut-ins, visiting mentally retarded children in special homes, and so on. These organizations wanted me to know how much they depend upon these volunteers, and they wanted some acknowledgement from me that I was aware of this selfless and invaluable service. Having been a volunteer for mental health causes in Georgia for many years, I myself am, of course, aware and I understand very well the value of the great volunteer spririt in this country. In my view, we can't have a caring, humane society with out it.

If we are going to make the progress that we know we must, I think will need increasing numbers of dedicated, and whenever possible, trained volunteers. When more volunteers become involved in mental health work, this not only expands our ability to provide help but builds an indreasing number of citizens who know the facts firsthand and who become powerful communicators to their families, friends and neighbors. An ever larger phere of the public is made aware of mental illness and what can be done about it. This, alone, could be an important factor in diminishing neagative attitudes and groundless fear and disdain among the public.

Organizations such as our Cancer Society and Heart Association have long since pursued the benefits of maximum volunteer involvement. as has our Mental Heatlh Association and its 38 chapters around the country. But comparative statistics concerning volunteer strength show once again, in yet another elooquent way, that the words "mental health" are apt to frighten off large numbers of otherwise well-meaning citizens. Consider this: the Cancer Society has $2\frac{1}{2}$ million volunteers and the Heart Association has two million. Our Mental Health Association has only about 230,000. There is no rational basis for these lopsided numbers. Twenty million Americans are in need of mental health care right now -- roughly 10% of thepopulation. -- whereas _____ Americans died of heart attacks last year and _____ of cancer. So it is not that mental illness is less common to our society than other major diseases; it is that mental illness is simply not an acceptable condition, not something very many people want to talk about or deal with. And that is why we are here today -- to learn how, for once and for all, we can effectively educate the public to more

relaxed and rational attitudes and feelings about mental illness.

All of us need to talk to the public as much as we talk to each other. We have as much to learn as to impart. Our Mental Health Asssociation has learned that the public still believes that most care of mental illness takes place in mental hospitals and that treatment is of a very long duration. Obviously, such frightening and threatening beliefs stand in the way of people admitting that they, or a member of their family, may needs care. Yet the fact is, as you all know, afer that almost all care of problems of coping -- better than 80% -- takes place on an out-patient basis, requiring absolutely no hospitalization. Even where hospitalization is indicated, it usually amounts to less than 17 days in spychiatric units of our general hospitals.

If we can just substitute these facts for the gross and disheartening misconceptions which prevail, we will have taken a great step forward toward helping people relax about the subject and even about their own possible need for care. We need to replace each myth with a reassuring truth -- and I think most of the truth is reassurring.

At our public hearing in Philadelphia, Senator Alexander Menza from New Jersey (speaking on behalf of the New Jersey Assn. for Mental Health) expressed an opinion which is very close to my own -- and it is why I entered the field of mental health in the first place. I will quote him:

> We should not get bogged down in over-intellectualizing the problems of mental illness, or talk forever on questions of funding, on the laws, on the jargon of deligery of service and all the cliches that are quite typical of the subject so that we forget what the President's Commission on Mental Health is all about. And that is simply to try to create a national commitment, a national attitude, a national climate for the proper care of treatment of the mentally ill. Because if we do this, the rest -- the laws, the governmental reorganziations, the funding, the services -- all of it will naturally fall into place.

in America

I believe that. I believe that in America, when the people speak, their government and their laws will listen and follow. When the people speak for good, when they put their most vulnerable citizens first, we can indeed look forward to a truly humanized society.

END

RSC's Vancouver Speech
Draft

not for press kit → ~~Thank you~~ (put add on Mrs C's cards)

It is an honor to be with you.

I am here today as a dedicated lay person in the midst of dedicated professionals.

And I would like to share with you some thoughts about our common goal.

I believe that goal to be a more caring society.

Not long ago, your founder, Margaret Mead, came to the White House to talk to me about my interest as a volunteer and citizen advocate for mental health and my job as Honorary Chairperson of the President's Commission on Mental Health.

She has so much knowledge and so much feeling.

I have admired her for years, and I was pleased to have the chance to benefit from her wisdom.

Dr. Mead tells me she believes that if we select for first consideration the most vulnerable among us -- the emotionally disturbed child, the institutionalized psychotic, the street addict -- then our whole culture is humanized.

She believes that our value as individuals, our success as a society, can be measured by our compassion for the vulnerable.

I think that all of us in the global mental health movement agree.

And yet something is wrong.

Something keeps holding us back.

And that is what I want to talk about today.

What is holding us back is the stigma that is attached to mental illness.

Negative public attitudes are holding back progress in our field.

And this self-feeding cycle of fear, discrimination, and lack of understanding about mental illness is more than a vague uneasiness we detect from time to time.

It is a troubling fact.

A study published a few years ago, e.g. reveals that out of 21 groups of disabled persons, the ex-convicts, the retarded, the alcoholics were least preferred -- were way down on the list -- but the mentally ill were the last.

And another survey of a community which undertook a massive public education program about mental illness shows public prejudices actively deepened and were worse afterward than before.

Listen to the words of Priscilla Allen, one of our 20 Commissioners ~~on the Commission~~. She is a former mental patient, and this is what she said at our very first meeting at the White House early this spring. "I am half in the closet and half out", Priscilla said. "I am a former patient, and I intended to have everyone on the Commission know that; but I did not want to announce it to the United States of America. With the press here, it was really difficult for me to identify myself. There is definitely a great deal of stigma attached to mental illness. I have been all over the United States -- Florida, Pennsylvania, and I live in California -- talking about mental health issues and about patients' rights issues. But the people in the place where I live do not know, most of them, that I am a former patient. I didn't tell the manager this when I filled out the form. When I told him later, he said he was glad he hadn't known because he would not have let me in."

This was the first time, but not the last, that the Commission heard in first-hand testimony from several hundred professionals and lay persons

about the pain and difficulties that former mental patients encounter out in the real world.

Consider Priscilla's problem -- and those of thousands of others -- whose right it is to have a decent place to live.

Where can they turn?

In spite of all our efforts, many people are still afraid to live next door to an ex-patient. They think that crime will increase; their children will be harmed; their property values reduced.

And although we recognize the necessity to take patients out of back rooms and closets and into community-based treatment centers, the public worries that these might be dangerous and irresponsible members of society.

In many communities in my country, sponsors of group homes have been forced to go to court and file suits when local zoning appeals boards have refused occupancy permits. In Massachusetts, New York, New Jersey, and California, however, judges have ruled that group homes can be established.

Clearly we must stop using zoning laws as weapons in the fight to keep ex-mental patients out of our communities.

Never mind that almost every family in that community might be touched in some way by depression, marital problems, drug and alcohol-related problems, the inability to cope as the result of a death or a serious accident, or simply low self-esteem.

The data our Commission has gathered shows that the public continues to be repelled by the notion of mental illness -- although it is becoming less socially acceptable to say so!

And what about getting a job if you have been labeled a mental patient?

During our Commission hearings, a Philadelphia labor leader admitted publicly that mental health care affects job security and advancement. He said, "It's very, very difficult to bring mental health concerns directly

Insert A

It's almost impossible to determine the magnitude of this problem because good data on the employment of people ~~wh~~ with a history of mental illness just doesn't exist. Ex-mental patients who succeed in the job market usually do so because they hide their past history.

into the workplace because of the stigma that is definitely attached to it.

And the mother of a 28 year old mentally ill son in San Francisco told us, "He could work, but the private enterprise is not going to give any jobs to the mentally ill. He could work, and it would have done more to have built back his self-confidence, which is completely gone, and his ego, which is at zero level, than any drug, anything I could do, anything we can ever do for him."

(Data forthcoming on rehabilitation and employment.) Insert A

And what about the dilemma that is caused by the differences in cultural heritage that prevent so many from seeking the care and treatment they rightly deserve?

Our Commission learned quickly from Hispanic Americans, Indians, and other minority groups that it is absolutely essential to develop within the mental health system a real sensitivity to their special needs.

We cannot impose the Euro-American standard of treatment on everyone, especially on those who are already alienated and excluded from the mainstream. We need to tailor services to ethnic and racial minorities, and we need to launch a broad attack against stigma in communities where these citizens live.

It is not going to be easy.

In San Francisco, for example, an Asian psychiatrist told us that his people "reject the idea of having a mentally ill member of the family because of feelings of fear, rejection and/or ridicule. Asian families tend to care for psychotics at home," he said, "postponing use of mental health services until an urgent situation arises."

Another witness in Tennessee told us about a woman in a migrant camp, whose name was never known, but who had been identified by a social worker

as being in desperate need of help.

When a staff member charged with Migrant Services tried to find and help her, he was told that no such woman existed and that the camp would not tolerate crazy people. Several days later her body was found by the side of the road, a victim of a hit-and-run driver.

Those of us here share a central mission to understand those things which bind people of different cultures together. Whether our traditions and heritage call for self reliance, strength, working out one's own difficulties, not burdening others with one's pain -- or whether we are moved by pride, fear or superstition -- we share our human condition.

We need to care and to be cared for.

But many people do not know how to reach out.

They will -- in order to avoid a label -- seek alternatives to professional help.

Studies show that the majority of persons do not go to professionals when they are bowed down with problems. They go to clergymen, family, friends, neighbors. They seek out a helper who is "safe" and will not brand them with disgrace.

The Institute for Social Research at the University of Michigan has just released research showing how Americans view their mental health. They have discovered that among people who seek help, slightly less than 70 percent do not go to mental health professionals.

The single most important reason for not getting care is because people feel they should solve their problems themselves.

The second reason they stay away is because of over-riding feelings of shame. And, significantly, this shame is twice as compelling as cost.

~~And please listen to this: the Michigan study shows that stigma is perceived as a bigger problem now than it was twenty years ago!~~

But even when the enlightened patient finally seeks out the mental health professional, there are attitudes that need to be scrutinized.

In San Francisco, I was told by a former patient: "Mrs. Carter, at the risk of offending many professionals in this room, I have run into as much prejudice and fear in the therapist as I have in the many people who encounter my history.

Another former patient told me, "At this point, many members of the mental health profession are so condescending to their clients that it is impossible to even talk to them."

So stigma is a problem in getting people into treatment in the first place; it's a problem during treatment; and it's a problem in trying to get a patient re-involved in the community.

In addressing himself to this subject at our first White House meeting, one of our distinguished Commissioners spoke out forcefully about the need for the understanding and acceptance of mental illness. He told us he did not believe that we were out of the closet at all. If we were, he reminded us, we would be getting the necessary funds for research and services from the federal, state and local governments. He says we aren't ever going to get that support until public attitudes change.

I think he is right.

We must start talking to the public as much as we talk to each other. We must expand our ranks. Consider this: in the United States our Cancer Society has 2½ million volunteers, our Heart Association has 2 million; our Mental Health Association has only about 230,000.

Yet there is not rational basis for these figures. Twenty million Americans are in need of mental health care right now -- roughly 10 percent of the population; whereas just over a million Americans died of heart attacks last year and more than 350,000 died of cancer.

So it is not that mental illness is less prevalent than other major diseases; it is that mental illness is simply not an acceptable condition people want to talk about or deal with.

And we all know this state exists because of the misconceptions that prevail.

We must work harder to replace each myth about mental illness with a reassuring truth.

We must stop over-intellectualizing, stop worrying about our jargon, and speak in simple, direct language that people can understand.

Let me tell you how a state senator from New Jersey suggested to me that we approach the issue. He said that in the United States we need to try to create a national commitment, a national attitude, a national climate for the proper care and treatment of the mentally ill. Because if we do this, he says, the rest -- the laws, the governmental reorganizations, the funding, the services -- all will fall naturally into place.

I believe that.

And I believe that is a message with global significance.

Those of us around the world -- in developing and developed nations -- must commit ourselves to the creation of a caring society with global bonds.

We must create a climate in which our most vulnerable are accepted.

We must start first with them.

Then the rest will fall naturally into place.

Remarks for World Federation For Mental Health - Rosalynn Carter

Vancouver, British Columbia, August 25, 1977

It is an honor to be with you. I am here today as a dedicated lay person in the midst of dedicated professionals. And I would like to share with you some thoughts about our common goal.

I believe that goal to be a more caring society.

Not long ago, your founder, Margaret Mead, came to the White House to talk to me about my interest as a volunteer and citizen advocate for mental health and my job as Honorary Chairperson of the President's Commission on Mental Health. She has so much knowledge and so much feeling. I have admired her for years, and I was pleased to have the chance to benefit from her wisdom.

Dr. Mead tells me she believes that if we select for first consideration the most vulnerable among us -- the emotionally disturbed child, the institutionalized psychotic, the street addict -- then our whole culture is humanized. She believes that our value as individuals, our success as a society, can be measured by our compassion for the vulnerable.

I think that all of us in the global mental health movement agree. And yet something is wrong. Something keeps holding us back. And that is what I want to talk about today.

What is holding us back is the stigma that is attached to mental illness. Negative public attitudes are holding back progress in our field. And this self-feeding cycle of fear, discrimination, and lack of understanding about mental illness is more than a vague uneasiness we detect from time to time. It is a troubling fact.

A study published a few years ago, e.g. reveals that our of 21 groups of disabled persons, the ex-convicts, the retarded, the alcoholics were least preferred -- were way down on the list -- but the mentally ill were the last.

And another survey of a community which undertook a massive public education program about mental illness shows public prejudices actively deepened and were worse afterward than before.

Listen to the words of Priscilla Allen, one of our 20 Commissioners. She is a former mental patient, and this is what she said at our very first meeting at the White House early this spring. "I am half in the closet and half out", Priscilla said. "I am a former patient, and I intended to have everyone on the Commission know that; but I did not want to announce it to the United States of America. With the press here, it was really difficult for me to identify myself. There is definitely a great deal of stigma attached to mental illness. I have been all over the United States --

Florida, Pennsylvania, and I live in California -- talking about mental health issues and about patients' rights issues. But the people in the place where I live do not know, most of them, that I am a former patient. I didn't tell the manager this when I filled out the form. When I told him later, he said he was glad he hadn't known because he would not have let me in."

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Consider Priscilla's problem -- and those of thousands of others — whose right it is to have a decent place to live. Where can they turn? In spite of all our efforts, many people are still afraid to live next door to an ex-patient. They think that crime will increase; their children will be harmed; their property values reduced.

And although we recognize the necessity to take patients out of back rooms and closets and into community-based treatment centers, the public worries that these might be dangerous and irresponsible members of society.

In many communities in my country, sponsors of group homes have been forced to go to court and file suits when local zoning appeals boards have refused occupancy permits. In Massachusetts, New York, New Jersey, and California, however, judges have ruled that group homes can be established. Clearly we must stop using zoning laws as weapons in the fight to keep ex-mental patients out of our communities. Never mind that almost every family in that community might be touched in some way by depression, marital problems, drug and alcohol-related problems, the inability to cope as the result of a deathor a serious accident, or simply low self-esteem.

The data our Commission has gathered shows that the public continues to be repelled by the notion of mental illness -- although it is becoming less socially acceptable to say so!

And what about getting a job if you have been labeled a mental patient? During our Commission hearings, a Philadelphia labor leader admitted publicly that mental health care affects job security and advancement. He said, "It's very, very difficult to bring mental health concerns directly into the work-place because of the stigma that is definitely attached to it."

And the mother of a 28 year old mentally ill son in San Francisco told us, "He could work, but the private enterprise is not going to give any jobs to the mentally ill. He could work and it would have done more to have built back his self-confidence, which is completely gone, and his ego, which is at zero level, than any drug, anything I could do, anything we can ever do for him."

It's almost impossible to determine the magnitude of this problem because good data on the employment of people with a history of mental illness just doesn't exist. Ex-mental patients who succeed in the job market usually do so because they hide their past history.

And what about the dilemma that is caused by the differences in cultural heritage that prevent so many from seeking the care and treatment they rightly deserve? Our Commission learned quickly from Hispanic Americans, Indians, and other minority groups that it is absolutely essential to develop within the mental health system a real sensitivity to their special needs.

We cannot impose the Euro-American standard of treatment on everyone, especially on those who are already alienated and excluded from the mainstream. We need to tailor services to ethnic and racial minorities, and we need to launch a broad attack against stigma in communities where these citizens live.

It is not going to be easy. In San Francisco, for example, an Asian psychiatrist told us that his people "reject the idea of having a mentally ill member of the family because of feelings of fear, rejection and/or ridicule. Asian families tend to care for psychotics at home," he said, "postponing use of mental health services until an urgent situation arises."

Another witness in Tennessee told us about a woman in a migrant camp, whose name was never known, but who had been identified by a social worker as being in desperate need of help. When a staff member charged with Migrant Services tried to find and help her, he was told that no such woman existed and that the camp would not tolerate crazy people. Several days later her body was found by the side of the road, a victim of a hit-and-run driver.

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We need to care and to be cared for. But many people do not know how to reach out. They will -- in order to avoid a label -- seek alternatives to professional help. Studies show that the majority of persons do not go to professionals when they are bowed down with problems. They go to clergymen, family, friends, neighbors. They seek out a helper who is "safe" and will not brand them with disgrace.

The Institute for Social Research at the University of Michigan has just released research showing how Americans view their mental health. They have discovered that among people who seek help, slightly less than 70 percent do not go to mental health professionals.

The single most important reason for not getting care is because people feel they should solve their problems themselves. The second reason they stay away is because of over-riding feelings of shame. And, significantly, this shame is twice as compelling as cost.

But even when the enlightened patient finally seeks out the mental health professional, there are attitudes that need to be scrutinized. In San Francisco, I was told by a former patient: "Mrs. Carter, at the risk of offending many professionals in this room, I have run into as much prejudice and fear in the therapist as I have in the many people who encounter my history.

Another former patient told me, "At this point, many members of the mental health profession are so condescending to their clients that it is impossible to even talk to them."

So stigma is a problem in getting people into treatment in the first place; it's a problem during treatment; and it's a problem in trying to get a patient re-involved in the community.

In addressing himself to this subject at our first White House meeting, one of our distinguished Commissioners spoke out forcefully about the need for the understanding and acceptance of mental illness. He told us he did not believe that we were out of the closet at all. If we were, he reminded us, we would be getting the necessary funds for research and services from the federal, state and local governments. He says we aren't ever going to get that support until public attitudes change.

I think he is right. We must start talking to the public as much as we talk to each other. We must expand our ranks. Consider this: in the United States our Cancer Society has 2½ million volunteers, our Heart Association has 2 million; our Mental Health Association has only about 230,000.

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Let me tell you how a state senator from New Jersey suggested to me that we approach the issue. He said that in the United States we need to try to create a national commitment, a national attitude, a national climate for the proper care and treatment of the mentally ill. Because if we do this, he says, the rest -- the laws, the governmental reorganizations, the funding, the services -- all will fall naturally into place.

I believe that. And I believe that is a message with global significance. Those of us around the world -- in developing and developed nations -- must commit ourselves to the creation of a caring society with global bonds. We must create a climate in which our most vulnerable are accepted. We must start first with them. Then the rest will fall naturally into place.

MEMORANDUM

THE WHITE HOUSE

WASHINGTON

August 24, 1977

TO: Mrs. Carter

FROM: Kathy

RE: Study on Public Attitudes Towards the Mentally Ill

The study you refer to in your speech was reported in the Journal of Special Education, 1970. It was cited by Judith Rabkin, New York State Department of Mental Hygiene, who is doing work for our Task Panel on Public Attitudes and the Media.

It was conducted by J.L. Tringo. He established a hierarchy of disability groups in terms of their relative social acceptability. Community members were asked to rate each of 21 disability groups on a 9-point social scale. (On this scale a rating of 1 signifies "would marry" and at the other extreme, a rating of 9 is "would put to death".)

He found that the most preferred were those with physical disabilities, then people with sensory handicaps. Of the 21 groups, the least preferred were the ex-convict, the mentally retarded, the alcoholic, and the mentally ill in last place.

While the age, education and social background of respondents influenced the overall extremeness of their ratings, the order remained the same among the different groups who were studied.

MEMORANDUM

THE WHITE HOUSE

WASHINGTON

August 24, 1977

TO: Mrs. Carter

FROM: Kathy Cade

RE: Survey by the Institute of Social Research, University of Michigan

The study you refer to by the Institute for Social Research is a repeat of a survey that was originally commissioned by the Joint Commission on Mental Health in 1956.

The data collection for this survey has just been completed. The sampling was done on a carefully selected group of 2500 people selected to be representative of the American population.

This recent survey makes it possible to compare attitudes now with those of 20 years ago.

The Center has been doing special analyses for the Commission. They have not yet published any of their results. They are now in the process of doing a comprehensive analysis of all the data.

FOR IMMEDIATE RELEASE August 25, 1977

OFFICE OF THE FIRST LADY'S PRESS SECRETARY

Fact Sheet

World Federation for Mental Health

The 1977 World Congress on Mental Health was convened on Sunday, August 21, 1977, in Vancouver, British Columbia, Canada, for a six-day review of mental health systems and current practices in order to establish "Today's Priorities in Mental Health".

The World Federation for Mental Health was founded in London in 1948 at the Third International Congress on Mental Health. Its founding meeting was attended by delegates of 46 countries and was sponsored by the International Committee for Mental Hygiene, which, since 1931, had promoted the formation of mental hygiene societies in different countries. Dr. Margaret Mead was a founding member and is a past president of the World Federation for Mental Health.

It is on the register of the Secretary General of the United Nations as a body to be consulted by the Economic and Social Council (ECOSOC), and it also has a consulting status with the United Nations Educational, Scientific and Cultural Organization (UNESCO), the World Health Organization (WHO) and the United Nations Childrens Fund (UNICEF).

The Secretariat of World Federation for Mental Health is located in London, its administrative offices in Geneva.

MEMORANDUM

THE WHITE HOUSE

WASHINGTON

TO: Mrs. Carter

FROM: Kathy

RE: Additional background on meeting with Dr. Sartorios and dinner

Meeting with Dr. Sartorios

Dr. Sartorios is Director of Mental Health for the World HEalth Organization. He is a psychiatrist and from Geneva, Switzerland. Dr. Brown, his assistant Pat Okura, Tom and I will be present.

The purpose of the meeting is to bring you up-to-date on international mental health activities.

Dinner

There will be four dinners going on Thursday night. You will be attending one. Margaret Mead will make remarks at the dinner. There will also be entertainment.

Kathy
FYI
Comments

THE WHITE HOUSE

WASHINGTON

file

October 3, 1977

MEMORANDUM TO MARY HOYT

FROM: PETER BOURNE P.B.

I thought the attached might be of interest to you.

PGB:ss

Attachment

c.c. Tom Bryant

I stand by our thesis! We know the data base is not terrific, we know situation is not as bad as it was years ago, but it still is an enormous problem.

Also — I think he's putting words in our mouths when he talks about "blaming" the public. I think we're just calling attention to the problem.

THE WHITE HOUSE

WASHINGTON

October 3, 1977

Dear Dr. Lemkau:

Thank you for your recent letter concerning Mrs. Carter's speech to the World Federation of Mental Health. I was not involved in anyway in the preparation of her speech. I am however, passing your comments along to her Press Secretary Mary Hoyt, whom I understand prepared her remarks for her. I am sure that she will find your comments most helpful.

Sincerely,

Peter G. Bourne

Peter G. Bourne, M.D.
Special Assistant to
the President

Paul V. Lemkau, M.D.
Professor
The John Hopkins University
615 North Wolfe Street
Baltimore, Maryland
21205

PGB:ss

THE JOHNS HOPKINS UNIVERSITY

SCHOOL OF HYGIENE AND PUBLIC HEALTH

DEPARTMENT OF MENTAL HYGIENE

615 North Wolfe Street • Baltimore, Maryland 21205

September 19, 1977

Dr. Peter Bourne
Office of the President
The White House
Washington, D. C.

Dear Dr. Bourne:

I was privileged to hear Mrs. Carter speak at the Congress of the World Federation for Mental Health in Vancouver recently and to meet her briefly afterward to congratulate her on the excellent presentation. You are probably aware of her generosity: in the course of the address she said "When we were working on this speech ... " or words to that effect. Many would, I think, not give this sort of recognition to the fact that such speakers require the effort of more than the speaker.

I presume you were one of the people who helped in the preparation or are, at least, in a position to influence the content of speeches by Mrs. Carter and other figures in the field connected with the government. For this reason I write you concerning the emphasis Mrs. Carter placed on the stigma associated with the mental diseases. The early part of her address echoed the last Presidential Commission Report -- stressing that stigma was an important factor interfering with progress in the field of mental health.

There are a number of reasons why I think this approach is harmful to the cause. In the first place, it seems to shift the burden to our too small success to be responsible to the public. This is a sort of "blaming the victim" and excusing ourselves which will tend to turn the public away rather than attract its interest to our field.

Secondly, I think the data in support of a high level of stigma in the public attitudes is not nearly as good as it has been depicted, and most bibliographies do not list the works, and there is a goodly number of them, that indicate that the public is more accepting than it is given credit for. Mrs. Carter did note that there are feelings of stigma among professionals, a factor few have noted in studies in this general area. I was glad to hear her make this point; it relieved the "blaming the victim" atmosphere considerably when done as gracefully as she accomplished it.

Of course, the studies are all deficient in that they almost always use all-inclusive categories of mental illness rather than the separate syndromes within psychiatry. I'm sure both you and I would advise our daughters (I have some; I don't know your status!) to be very cautious about marrying a man who had had any recent schizophrenic type illness. This would not, in my estimation, be an evidence of stigma, but a simple recognition of what we know of relapse rates and of the genetics of schizophrenia. On the other hand, we might welcome one who had some neurotic complaint or perhaps a depression. The Star cases were not used to test the way the public might react to different kinds of mental illness; they were used to test its "ability to recognize syndromes as mental." Given a sample of the violent paranoid patient in the same group as the alcoholic, etc., it is no wonder some cautionary attitudes would appear in responses from the public.

Finally, our very success in reducing the population of mental hospitals in the last decades, and the success of treatment in the community bear witness to the fact that the public will accept identified patients in their midst. Generally speaking, our patients ill enough to require hospitalization are not fully recovered when discharged, but their families usually are anxious to get them home as soon as possible, often before their doctors feel they should go home. This does not strike me as an evidence of stigma against the patient. I'm not sure it means simply getting away from a hated institution, the psychiatric hospital, either. I have

wondered, however, why families should not want to get their members out of state hospitals as soon as possible. God knows, we have to testify to how much the hospitals leave to be desired each time we go before the legislature to justify their budgets. Do we expect the public not to listen to what we say in such testimony?

My purpose in writing this to you is to try to enlist your help in modifying Mrs. Carter's addresses so that stigma on the part of the public will not be stressed as much. Her generous nature doesn't, to me, appear comfortable with an attitude of blaming anybody. I believe she would be more comfortable (and probably more accurate, scientifically) if she were encouraged to find some other "take off" point for her addresses.

Very sincerely yours,

Paul Lemkau, MD

PAUL V. LEMKAU, M. D.
PROFESSOR

PVL:j

p.S. Since drafting this letter, I note in the "Psychiatric News" of September 2, 1977, that there is to be a special report by a Task Panel on media and public attitudes which will deal with the issue of stigma. I will prepare a letter with content similar to this for that panel's consideration.

Paul V. Lemkau, M.D.

MEMORANDUM

THE WHITE HOUSE

WASHINGTON

August 23, 1977

TO: RSC

FROM: Mary Hoyt

RE: Press on Plane to Vancouver

At the present time, the reporters listed below will fly to Canada with us. I have granted several interviews on the trip which we can schedule whenever you wish.

We have also scheduled almost two hours of Canadian and West Coast press for Friday morning before departure as per your approval.

Dennis Farney, Wall Street Journal, is doing a front-page feature about you. Has asked for thirty minutes on the way out and perhaps 15-20 minutes on the way back after he has observed you in action.

Paul Healy, New York Daily News, has asked for a forty-minute interview for a three-part series he is doing on you, the President, and the family.

Ann Morrow, London Daily Telegraph, has asked only for ten minutes but hopes you will take twenty to know what she is talking about.

Ann Compton, ABC, is picking up a crew in Vancouver. No interview schedule.

Lee Thornton, CBS, is picking up a crew in Vancouver. No interview scheduled.

Julie Moon, US Agent News, no interview requested.

212-873-1300

MARGARET MEAD
15 WEST 77TH STREET
NEW YORK, NEW YORK 10024

August 17, 1977

Dear Ms. Hoyt,

We are enclosing Dr. Mead's speech for the World Federation for Mental Health to which Mrs. Carter may want to refer. Dr. Mead's speech will be given, as we understand it, two days before Mrs. Carters'.

Sincerely,

Carol Zwick

Carol Zwick
Assistant to Dr. Mead

Mary Finch Hoyt
Press Secretary
to Mrs. Carter
The White House
Washington, D.C.

Knowing, Reaching, and Serving the Wounded, the Disadvantaged and Vulnerable of Our World

(draft of the address which Margaret Mead will deliver at the meeting of the World Federation for Mental Health, in Vancouver, August 23, 1977)
Not for reproduction except for discussants

The task of the World Federation is to develop a world wide ethic which is wide enough to include all the peoples of the world and flexible enough so that each constituent member can contribute to it. Throughout the 29 years in which the World Federation has been existent, this task has been a major concern; the first deliberations of the Preparatory Commission at Roffrey Park in 1948 - when we had to deal with the problem of whether mental health principles could be reconciled with totalitarianism and solve the question of Nazism by recognizing that Nazism had been a pathology not a culture - to the development of anything that could be called a culture took three generations. Our understanding expanded with a recognition of some of the earlier statements about the extent to which mental health involved an ability to stand on one's feet; these read rather comically like Kipling's "If":

> If you can keep your head when all about you
> Are losing theirs and blaming it on you
> If you can trust yourself when others doubt you
> And being doubted not to take to doubting too!

It was expanded further when we drew together representatives of 29 countries, a great variety of specialists concerned with the development of infants and young children, at Chichester in 1952, and pled with representatives of those countries which had never separated the newborn from their mothers in nurseries not to imitate our contemporary practice. It was also widened at Chichester when the male members of the Seminar rebelled against the excessive emphasis, current at the time, on the

mother and child dyad, to which there was a growing tendency to add the department of public health, rather than a participating father, as the third member of the triad. When the First Asian Seminar on Mental Health and Family Life was held in Baguio, in the Philippines in 1958, we had come face to face with the differences between the individual-centered cultures of Western Europe and North America and the family centered cultures of Asia. In studies of identity, of the ways in which mental health principles articulate with the great religions and with different political ideologies, we have struggled through the years to widen and deepen our understanding of how treatment should be given to those in need, prevention inaugurated to anticipate breakdowns before they occur, and nurturing cherishing and rehabilitation extended to groups in need, not hitherto recognized either by the world at large or by many of the world's societies.

It is important, I believe, to reaffirm that any ideal which we advocate, as members of the World Federation for Mental Health, in a world congress assembled, must be relevant to the whole world. Although in particular cases, when temporary disregard of human values characterises the political condition of some society, these ideals can only nourish the responsible dissidents rather than those who are planning for the society they govern. It is from this point of view that I wish to examine the phrases, <u>wounded</u>, <u>disadvantaged</u> and <u>vulnerable</u>. All three sound as if they might be regarded as universals, as what we sometimes call "stripped universals", but each has to be examined to work out the implications for different cultures, different religious beliefs, different ideologies and different conditions of modernization.

The English word wounded immediately calls up images of war and the needs of those who have been wounded, mutilitated, or disabled in warfare. Yet in every society which takes upon itself the care of veterans, those wounded in battle, who have hospital care, rehabilitation and economic benefits, may be among the specially advantaged. The rehabilitation itself may take very different forms; in some countries the paraplegic is provided with a driver, in others, he is expected to learn to drive himself with a specially designed car. The loss of a leg may be paraded to elicit pity or camouflaged as completely as possible with a prothesis. In traditional Bali, any permanent tear or loss to the body, like a torn earlobe or a fingernail that fails to grow back, may mean social disqualification for a life time though it is compensated for, to some extent, by a belief in reincarnation. The estate of those who suffer some conspicuous physical deprivation, like blindness or loss of limb, is very different in a society in which they can anticipate further and more felicitous reincarnations than in one like our own where there is only one earthly life to be lived and where every loss is in fact irreparable. Part of society's obligation is to make restitution for such irreparable loss.

We may know, from detailed studies of infants separated prematurely from their mothers, that the death of a mother in childbirth is in fact a loss which can not be compensated for. Nevertheless, it is a very different loss when the infant's cowife is her sister, where it is customary for women to breast feed the infants of others, and where the tie between a woman and her child is established not because she shelters the growing life in the womb but because she provides it the milk upon which it feeds.

The cross cultural studies of child development, which have been included in the deliberations of the World Federation for Mental Health since its inception, will continue to provide us with new solutions to ancient problems, solutions which in some cases can be incorporated in the practises of modern societies or the modernized styles of ancient or recently organized nation states. So although the advantages of breast feeding for the health of mother and infant have been recurrent themes, the emphasis has shifted from efforts to study the infant's rhythm, by the use of clock and pencil and paper, to the importance of breast feeding as a way of preventing the forced separation of mother and child in the hospital or the use of excessively expensive powdered milk. More recently, the synergistic effect of better nutrition for the breast feeding woman, which contributes to the health of the infant, a longer period of fertility in the lactating woman, an increase in the chances of the child's survival (and therefore secondarily to the willingness of parents to have fewer children) has been emphasized.

In 1953, in Cultural Patterns and Technical Change, we discussed the mental health hazards to which the second generation of immigrants were exposed; today it may be necessary to seriously question schemes for transmigration such as those in Indonesia, which hardly relieve population pressure but, by providing a supposed solution, reduce the responsibility to limit population growth.

So it is a continuing responsibility of the Federation to monitor the new research findings, new health technologies - powdered milk, plastic feeding bottles, feasible methods of monitoring ovulation, operations on cleft palates, amniocentesis, interventions in cases of spina bifida,

or RH negative mothers, mechanical simulation of the maternal heart beat for hospitalized infants - and the ways in which these progressive developments alter the world climate of Euro-American or Eastern European bases of opinion, internationally propogated standards of health care, and design of public institutions like hospitals, health centers, baby clinics, etc. These innovations, which often embody tremendous advances in neurosurgery, chemical synthesis, or electronic simulation, may also set in motion, in different parts of the world, unexpected and unfortunate trains of events, as for example, the introduction of rubber sheeting between the layers of swaddling on an infant, or the use of a miniscule amount of powdered milk to color contaminated water as a substitute for milk.

In every aspect of life in which the fate of human beings is involved and in every part of the world, we find reflections of the vicissitudes of the Euro-American world as we struggle, often in vain, with the tremendous complications produced by our over technologized post-WWII society. There is a shocking discrepency between arguments in the U.S. as to how we are to decide which candidates for a kidney transplant or a kidney machine are to be preferred over others and the discussion, in other countries, of measures needed to prevent the deaths of thousands in one week. The particular sensitivities which uderlie the mental health movement came from affluent industrialized societies where there was sufficient time and liesure for clinicians to spend hundreds of hours listening to the troubles of a single distressed adult or tying to bring back the lost power of speech to an autistic child. Perhaps this is the only way it could have happened, that the single individual human life could assume such an overwhelming significance that from it we could develop an ethic in which we could propose judging a social system

in terms of its willingness or unwillingness to sacrifice single individuals.

But within the affluent countries themselves, increasingly large groups of the neglected and discarded, the juvenile delinquents, institutionalized children, runaways, unemployables, recidivist prisoners, individuals destroying themselves or attempting to destroy the unresponsive urban wastelands within which they were born and are attempting to survive, can be found. Side by side with the provisions for speech therapy for a stuttering child or transportation for a student with cerebral palsy or special psychiatric treatment for a disturbed adolescent, and all the sequels of the mental health movement and sensitivity it has engendered, we find appalling insensitivities, such as the current U.S. indifference to the plight of hundreds of thousands of Vietnam war veterans, the unemployed, the despairing turning to the transient comforts of alcohol and drugs.

In the councils of the World Federation, we have long been aware of the glaring discrepancies between nations states when we have discussed, in the same program, the well being of populations where there is one psychiatrist per 2 million people and the delicate distinctions between different types of therapy or the relative advantages of drug therapy over psychoanalysis. The slight, but recognizable traumatization of children separated from their parents in American or English hospitals makes a sharp contrast to the plight of a hundred thousand children doomed to continuing malnutrition from birth in some country ravaged by war and famine.

Certainly, dilution of our areas of sensitivity cannot be the answer. But, any discussion within one framework, within the explicit ideals of the World Mental Health movement - when we first met in London

in 1948 or when we meet now - must deal with these tremendous problems of sheer scale. So in the World Federation for Mental Health sponsored meeting on the plight of refugees we had to discuss, in one breath, the consequences of the U.S. refusal to take refugees with a history of tuberculosis, Sweden's willingess to do so when the overstrained resources of Austria were contending with the breakdown in the Hungarian refugee camps, and the Mental Health Society of Hong Kong, itself confronted with refugee situations far more extensive and unmanageable, which sent a contribution of two guineas to help the European effort!

So when we try to translate a term like vulnerable in ways that will apply to those whom we care for, and those whom we fail so dismally to care for within affluent societies, and then to translate it further into measures that can be taken in countries where 30 and 40 per cent of the population is under 15, we find that one precaution against despair is a continuous active awareness of these differences. But I do not believe the answer can be sought in some crude terms such as sharing economic resources and cutting down on what good rehabilitation and preventive programs we have. In the United States at present, a great variety of programs designed to mitigate the evils attendant on industrialization and to provide the resources of modern medicine and modern knowledge of human behavior, are being summarily closed down because of economic stringency ; I fear that this may also happen in the European countries which are most advanced in their concern and care for the individual child or adult in need. This is, I think, a topic that should be discussed at this Congress.

No matter how different the solutions have to be, in a land of a thousand villages without electricity, and a modern city which may

be plunged into chaos because of a power grid failure, it seems reasonably clear that most of the criticisms as well as most of the basic advocacies of the use of modern technology must come from within the older industrialized countries. The strengths of modernization, powered by corporate interests and ideologies in which the hopes of the industrial revolution are still imbedded is such that only as the older systems recognize the defects of their own systems, are the less industrialized countries likely to follow suit. Within the Federation we have emphasized, for almost three decades, that a country that introduces maternity hospitals does not need to repeat such mistakes as treating child birth as if it were a surgical event, or segregating infants in large nurseries and impairing their capacity to suck by feeding them initially from bottles. But such efforts have been reasonably unproductive. In recent meetings on appropriate technology for Indonesia, I found the greatest impediment to useful communication was the way in which planners have incorporated the need - conceived of now as virtually a human right - to make the same mistakes as the affluent countries that industrialized a century ago. Only if emphasis is laid upon the adoption of some corrective measures to the large scale and overcentralization of industrialized societies, and upon solutions which are being adopted in the United States, Western Europe, Japan, or where the ideology is socialism - in USSR or The Peoples Republic of China - is there much hope that the leaders of younger nations, who are trained in the industrialized countries, will respond. I was told recently by a South East Asian who occupied an important transitional position in the health field, that women had to be regarded as "defective milk producing machines".

Yet mental health principles, founded in respect for the needs of every human being, and stated sufficiently abstractly, can be

applied cross culturally and cross ideologically if ample attention is paid to the differences and if viable universals can be identified. It then becomes the task of the World Federation to stress such universals and one of the most effective and persuasive ways of doing so is to identify the ways in which they apply in many different parts of the world. An example is the general principle that both children and adults survive stress, trauma, and disaster best if families and neighborhoods are kept together. This was a finding during the evacuation in the first days of World War II in Great Britain; these principles were advocated by mental health specialists during the terrible floods in the Netherlands in the mid 1950's, and were seriously disregarded in the recent Appalachian disaster in the United States when expensive trailers were provided to the victims of a mine avalanche but families and neighborhoods were totally disrupted. After a series of earthquakes in Greece, soon after the World Federation for Mental Health Seminar in Chichester, the Greek representative, using her knowledge of "mental health" found that what the village victims wanted most were tools to use in rescuing the harvest. In a world in which massive disasters are the accompaniment of over centralization, unmanageable population increases, and overly inter-dependent power and marketing systems, disasters are becoming more frequent, and the exchange of information on the care of survivors more urgent.

The World Federation was started as a global effort long before there was very much global thinking. J.R. Rees and Frank Fremont-Smith ranged the world, looking for gifted and innovative people who could bring to the Federation their culturally diversified insights from

Taiwan, Nigeria, the Philippines, Thailand, the Sudan, and Peru. The task that confronts us now is enormously harder than it was in 1948 or even in 1968, when the full predicament of a world society that had made the wrong choices had not yet fully dawned upon us.

I believe that the principles which we adopted at the beginning - respect for each individual, respect for each culture, and a belief that knowledge could be used to give human beings a fuller and better life - can provide the basis for what has to be done next.

VANCOUVER, BRITISH COLUMBIA AUGUST 25, 1977

REMARKS FOR WORLD FEDERATION FOR MENTAL HEALTH

THANK YOU.

IT IS AN HONOR TO BE WITH YOU.

I AM HERE TODAY AS A DEDICATED LAY PERSON IN THE MIDST OF DEDICATED PROFESSIONALS.

AND I WOULD LIKE TO SHARE WITH YOU SOME THOUGHTS ABOUT OUR COMMON GOAL.

I BELIEVE THAT GOAL TO BE A MORE CARING SOCIETY.

NOT LONG AGO, YOUR FOUNDER, MARGARET MEAD, CAME TO THE WHITE HOUSE TO TALK TO ME ABOUT MY INTEREST AS A VOLUNTEER AND CITIZEN ADVOCATE FOR MENTAL HEALTH AND MY JOB AS HONORARY CHAIRPERSON OF THE PRESIDENT'S COMMISSION ON MENTAL HEALTH.

~~SHE HAS SO MUCH KNOWLEDGE AND SO MUCH FEELING.~~

I HAVE ADMIRED HER FOR YEARS, AND I WAS PLEASED TO HAVE THE CHANCE TO BENEFIT FROM HER WISDOM.

DR. MEAD TELLS ME SHE BELIEVES THAT IF WE SELECT FOR FIRST CONSIDERATION THE MOST VULNERABLE AMONG US -- such as THE EMOTIONALLY DISTURBED CHILD, THE INSTITUTIONALIZED PSYCHOTIC, THE STREET ADDICT -- THEN OUR WHOLE CULTURE IS HUMANIZED.

SHE BELIEVES THAT OUR VALUE AS INDIVIDUALS, OUR SUCCESS AS A SOCIETY, CAN BE MEASURED BY OUR COMPASSION FOR THE VULNERABLE.

I THINK THAT ALL OF US IN THE GLOBAL MENTAL HEALTH MOVEMENT AGREE.

AND YET SOMETHING IS WRONG.

SOMETHING KEEPS HOLDING US BACK.

AND THAT IS WHAT I WANT TO TALK ABOUT TODAY.

WHAT IS HOLDING US BACK IS THE STIGMA THAT IS ATTACHED TO MENTAL ILLNESS.

NEGATIVE PUBLIC ATTITUDES ARE HOLDING BACK PROGRESS IN OUR FIELD.

AND THIS SELF-FEEDING CYCLE OF FEAR, DISCRIMINATION, AND LACK OF UNDERSTANDING ABOUT MENTAL ILLNESS IS MORE THAN A VAGUE UNEASINESS WE DETECT FROM TIME TO TIME.

IT IS A very real and TROUBLING FACT.

A STUDY PUBLISHED A FEW YEARS AGO, [redacted] REVEALS THAT [redacted] OUT OF 21 GROUPS OF DISABLED PERSONS, THE EX-CONVICTS, THE RETARDED, THE ALCOHOLICS WERE LEAST PREFERRED -- WERE WAY DOWN ON THE LIST -- BUT THE MENTALLY ILL WERE THE LAST.

AND ANOTHER SURVEY OF A COMMUNITY WHICH UNDERTOOK A MASSIVE PUBLIC EDUCATION PROGRAM ABOUT MENTAL ILLNESS SHOWS PUBLIC PREJUDICES ACTIVELY DEEPENED AND WERE WORSE AFTERWARD THAN BEFORE.

LISTEN TO THE WORDS OF PRISCILLA ALLEN, ONE OF OUR 20 COMMISSIONERS. SHE IS A FORMER MENTAL PATIENT, AND THIS IS WHAT SHE SAID AT OUR VERY FIRST MEETING AT THE WHITE HOUSE EARLY THIS SPRING. "I AM HALF IN THE CLOSET AND HALF OUT", PRISCILLA SAID. "I AM A FORMER PATIENT, AND I INTENDED TO

HAVE EVERYONE ON THE COMMISSION KNOW THAT; BUT I DID NOT WANT TO ANNOUNCE IT TO THE UNITED STATES OF AMERICA. WITH THE PRESS HERE, IT WAS REALLY DIFFICULT FOR ME TO IDENTIFY MYSELF. THERE IS DEFINITELY A GREAT DEAL OF STIGMA ATTACHED TO MENTAL ILLNESS. I HAVE BEEN ALL OVER THE UNITED STATES -- FLORIDA, PENNSYLVANIA, AND I LIVE IN CALIFORNIA -- TALKING ABOUT MENTAL HEALTH ISSUES AND ABOUT PATIENTS' RIGHTS ISSUES. BUT THE PEOPLE IN THE PLACE WHERE I LIVE DO NOT KNOW, MOST OF THEM, THAT I AM A FORMER PATIENT. I DIDN'T TELL THE MANAGER THIS WHEN I FILLED OUT THE FORM. WHEN I TOLD HIM LATER, HE SAID HE WAS GLAD HE HADN'T KNOWN BECAUSE HE WOULD NOT HAVE LET ME IN."

THIS WAS THE FIRST TIME, BUT NOT THE LAST, THAT ~~THE~~ OUR COMMISSION HEARD IN FIRST-HAND TESTIMONY FROM SEVERAL HUNDRED PROFESSIONALS AND LAY PERSONS ABOUT THE PAIN AND DIFFICULTIES THAT FORMER MENTAL PATIENTS ENCOUNTER OUT IN THE REAL WORLD.

CONSIDER PRISCILLA'S PROBLEM -- AND THOSE OF THOUSANDS OF OTHERS -- WHOSE RIGHT IT IS TO HAVE A DECENT PLACE TO LIVE.

WHERE CAN THEY TURN?

IN SPITE OF ALL OUR EFFORTS, MANY PEOPLE ARE STILL AFRAID TO LIVE NEXT DOOR TO ~~AN EX~~ A FORMER-PATIENT. THEY THINK THAT CRIME WILL INCREASE; THEIR CHILDREN WILL BE HARMED; THEIR PROPERTY VALUES REDUCED.

AND ALTHOUGH ~~WE~~ WE RECOGNIZE THE NECESSITY TO TAKE PATIENTS OUT OF BACK ROOMS AND ~~CLOSETS~~ institutions AND INTO COMMUNITY-BASED TREATMENT CENTERS, THE PUBLIC WORRIES THAT THESE MIGHT BE DANGEROUS AND IRRESPONSIBLE MEMBERS OF SOCIETY.

I've had first hand experience with this.

IN MANY COMMUNITIES IN MY COUNTRY, SPONSORS OF GROUP HOMES HAVE BEEN FORCED TO GO TO COURT AND FILE SUITS WHEN LOCAL ZONING APPEALS BOARDS HAVE REFUSED OCCUPANCY PERMITS. IN MASSACHUSETTS, NEW YORK, NEW JERSEY, AND CALIFORNIA, HOWEVER, JUDGES HAVE RULED THAT GROUP HOMES CAN BE ESTABLISHED.

CLEARLY WE MUST STOP USING ZONING LAWS AS WEAPONS IN THE FIGHT TO KEEP ~~EX~~ FORMER-MENTAL PATIENTS OUT OF OUR COMMUNITIES.

NEVER MIND THAT ALMOST EVERY FAMILY IN THAT COMMUNITY MIGHT BE TOUCHED IN SOME WAY BY DEPRESSION, MARITAL PROBLEMS, DRUG AND ALCOHOL-RELATED PROBLEMS, THE INABILITY TO COPE AS THE RESULT OF A DEATH OR A SERIOUS ACCIDENT, OR SIMPLY LOW SELF-ESTEEM.

THE DATA OUR COMMISSION HAS GATHERED SHOWS THAT THE PUBLIC CONTINUES TO BE REPELLED BY THE NOTION OF MENTAL ILLNESS -- ALTHOUGH IT IS BECOMING LESS SOCIALLY ACCEPTABLE TO SAY SO!

AND WHAT ABOUT GETTING A JOB IF YOU HAVE BEEN LABELED A MENTAL PATIENT?

DURING OUR COMMISSION HEARINGS, A PHILADELPHIA LABOR LEADER ADMITTED PUBLICLY THAT MENTAL HEALTH CARE AFFECTS JOB SECURITY AND ADVANCEMENT. HE SAID, "IT'S VERY, VERY DIFFICULT TO BRING MENTAL HEALTH CONCERNS DIRECTLY INTO THE WORKPLACE BECAUSE OF THE STIGMA THAT IS DEFINITELY ATTACHED TO IT."

AND THE MOTHER OF A 28 YEAR OLD MENTALLY ILL SON IN SAN FRANCISCO TOLD US, "HE COULD WORK, BUT THE PRIVATE ENTERPRISE IS NOT GOING TO GIVE ANY JOBS TO THE MENTALLY ILL. HE COULD WORK, AND IT WOULD ~~HAVE DONE~~ do MORE TO ~~HAVE~~ BUILD BACK HIS SELF-CONFIDENCE, WHICH IS COMPLETELY GONE, AND HIS EGO, WHICH IS AT ZERO LEVEL, THAN ANY DRUG, ANYTHING I COULD DO, ANYTHING WE CAN EVER DO FOR HIM."

IT'S ALMOST IMPOSSIBLE TO DETERMINE THE MAGNITUDE OF THIS PROBLEM BECAUSE GOOD DATA ON THE EMPLOYMENT OF PEOPLE WITH A HISTORY OF MENTAL ILLNESS JUST DOESN'T EXIST. ~~EX~~ Former-MENTAL PATIENTS WHO SUCCEED IN THE JOB MARKET USUALLY DO SO BECAUSE THEY HIDE THEIR PAST HISTORY.

AND WHAT ABOUT THE DILEMMA THAT IS CAUSED BY THE DIFFERENCES IN CULTURAL HERITAGE THAT PREVENT SO MANY FROM SEEKING THE CARE AND TREATMENT THEY RIGHTLY DESERVE?

OUR COMMISSION LEARNED QUICKLY FROM HISPANIC AMERICANS, INDIANS, AND OTHER MINORITY GROUPS THAT IT IS ABSOLUTELY ESSENTIAL TO DEVELOP WITHIN THE MENTAL HEALTH SYSTEM A REAL

IN SAN FRANCISCO, FOR EXAMPLE, AN ASIAN PSYCHIATRIST TOLD US - IN DESCRIBING THE CULTURAL HERITAGE OF HIS PEOPLE - that MANY ASIAN-AMERICANS ARE ESPECIALLY RELUCTANT TO ACKNOWLEDGE THAT A MEMBER OF THE FAMILY IS MENTALLY ILL. THEY FEAR THAT THE FAMILY WILL BE REJECTED AND RIDICULED IN THE COMMUNITY. THIS LEADS THEM TO TRY TO CARE FOR THE FAMILY MEMBER IN THE HOME, WITHOUT SEEKING NEEDED PROFESSIONAL HELP.

SENSITIVITY TO THEIR SPECIAL NEEDS.

WE CANNOT IMPOSE THE EURO-AMERICAN STANDARD OF TREATMENT ON EVERYONE, ESPECIALLY ON THOSE WHO ARE ALREADY ALIENATED AND EXCLUDED FROM THE MAINSTREAM. WE NEED TO TAILOR SERVICES TO ETHNIC AND RACIAL ~~MINORITIES~~ Groups, AND WE NEED TO LAUNCH A BROAD ATTACK AGAINST STIGMA IN COMMUNITIES WHERE THESE CITIZENS LIVE.

IT IS NOT GOING TO BE EASY.

IN SAN FRANCISCO, FOR EXAMPLE, AN ASIAN PSYCHIATRIST ~~and [illegible]~~ in describing the cultural heritage of his people - TOLD US ~~THAT HIS PEOPLE REJECT THE IDEA OF HAVING A MENTALLY~~ that many Asian-Americans are especially reluctant to ~~ILL MEMBER OF THE FAMILY BECAUSE OF FEELINGS OF FEAR, REJECTION~~ acknowledge that a member of the family is mentally ill. ~~AND/OR RIDICULE. ASIAN FAMILIES TEND TO CARE FOR PSYCHOTICS~~ They fear that the family will be rejected and ridiculed. ~~AT HOME," HE SAID, "POSTPONING USE OF MENTAL HEALTH SERVICES~~ in the community. This leads them to try to care for ~~UNTIL AN URGENT SITUATION ARISES.~~ the family member in the home, without seeking needed professional help.

ANOTHER WITNESS IN TENNESSEE TOLD US ABOUT A WOMAN IN A MIGRANT CAMP, ~~WHOSE NAME WAS NEVER KNOWN, BUT~~ WHO HAD BEEN IDENTIFIED BY A SOCIAL WORKER AS BEING IN DESPERATE NEED OF HELP.

WHEN A STAFF MEMBER CHARGED WITH MIGRANT SERVICES TRIED TO FIND AND HELP HER, HE WAS TOLD THAT NO SUCH WOMAN EXISTED AND THAT THE CAMP WOULD NOT TOLERATE CRAZY PEOPLE. ~~SEVERAL DAYS LATER HER BODY WAS FOUND BY THE SIDE OF THE ROAD, A VICTIM OF A HIT AND RUN DRIVER.~~

she was there — but she was never reached for help - & later was the victim of a fatal accident.

THOSE OF US HERE SHARE A CENTRAL MISSION TO UNDERSTAND THOSE THINGS WHICH BIND PEOPLE OF DIFFERENT CULTURES TOGETHER. WHETHER OUR TRADITIONS AND HERITAGE CALL FOR SELF RELIANCE, STRENGTH, WORKING OUT ONE'S OWN DIFFICULTIES, NOT BURDENING OTHERS WITH ONE'S PAIN -- OR WHETHER WE ARE MOVED BY PRIDE, FEAR OR SUPERSTITION -- WE SHARE OUR HUMAN CONDITION.

WE NEED TO CARE AND we need TO BE CARED FOR.

BUT MANY PEOPLE DO NOT KNOW HOW TO REACH OUT.

THEY WILL -- IN ORDER TO AVOID A LABEL -- SEEK ALTERNATIVES TO PROFESSIONAL HELP.

By coincidence

STUDIES SHOW THAT THE MAJORITY OF PERSONS DO NOT GO TO PROFESSIONALS WHEN THEY ARE BOWED DOWN WITH PROBLEMS. THEY GO TO CLERGYMEN, FAMILY, FRIENDS, NEIGHBORS, THEY SEEK OUT A HELPER WHO IS "SAFE" AND WILL NOT BRAND THEM ~~WITH DISGRACE~~.

THE INSTITUTE FOR SOCIAL RESEARCH AT THE UNIVERSITY OF MICHIGAN HAS JUST RELEASED RESEARCH data SHOWING HOW AMERICANS VIEW THEIR MENTAL HEALTH. THEY HAVE DISCOVERED THAT AMONG PEOPLE WHO SEEK HELP, SLIGHTLY LESS THAN 70 PERCENT DO NOT GO TO MENTAL HEALTH PROFESSIONALS.

THE SINGLE MOST IMPORTANT REASON FOR NOT GETTING CARE IS BECAUSE PEOPLE FEEL THEY SHOULD SOLVE THEIR PROBLEMS THEMSELVES.

THE SECOND REASON THEY STAY AWAY IS BECAUSE OF OVER-RIDING FEELINGS OF SHAME. AND, SIGNIFICANTLY, THIS SHAME IS TWICE AS COMPELLING AS COST.

BUT EVEN WHEN THE ENLIGHTENED PATIENT FINALLY SEEKS OUT THE MENTAL HEALTH PROFESSIONAL, THERE ARE ATTITUDES THAT NEED TO BE SCRUTINIZED.

IN SAN FRANCISCO, I WAS TOLD BY A FORMER PATIENT: "MRS. CARTER, AT THE RISK OF OFFENDING MANY PROFESSIONALS IN THIS ROOM, I HAVE RUN INTO AS MUCH PREJUDICE AND FEAR IN THE THERAPIST AS I HAVE IN THE MANY PEOPLE WHO ENCOUNTER MY HISTORY."

ANOTHER FORMER PATIENT TOLD ME, "AT THIS POINT, MANY MEMBERS OF THE MENTAL HEALTH PROFESSION ARE SO CONDESCENDING TO THEIR CLIENTS THAT IT IS IMPOSSIBLE TO EVEN TALK TO THEM."

SO STIGMA IS A PROBLEM IN (1) GETTING PEOPLE INTO TREATMENT IN THE FIRST PLACE; IT'S (2) A PROBLEM DURING TREATMENT; AND IT'S A PROBLEM IN (3) TRYING TO GET A PATIENT RE-INVOLVED IN THE COMMUNITY.

IN ADDRESSING HIMSELF TO THIS SUBJECT AT OUR FIRST WHITE HOUSE MEETING, ONE OF OUR ~~DISTINGUISHED~~ COMMISSIONERS SPOKE ~~OUT FORCEFULLY~~ ABOUT THE NEED FOR ~~THE~~ UNDERSTANDING AND ACCEPTANCE OF MENTAL ILLNESS. HE TOLD US HE DID NOT BELIEVE

THAT WE WERE OUT OF THE CLOSET AT ALL. IF WE WERE, HE RIMINDED US, WE WOULD BE GETTING THE NECESSARY FUNDS FOR RESEARCH AND SERVICES FROM THE FEDERAL, STATE AND LOCAL GOVERNMENTS. HE SAYS WE AREN'T EVER GOING TO GET THAT SUPPORT UNTIL PUBLIC ATTITUDES CHANGE.

I THINK HE IS RIGHT.

WE MUST START TALKING TO THE PUBLIC AS MUCH AS WE TALK TO EACH OTHER. WE MUST EXPAND OUR RANKS. CONSIDER THIS: IN THE UNITED STATES OUR CANCER SOCIETY HAS 2½ MILLION VOLUNTEERS, OUR HEART ASSOCIATION HAS 2 MILLION; OUR MENTAL HEALTH ASSOCIATION HAS ONLY ABOUT 230,000.

YET ~~THERE IS NOT RATIONAL BASIS FOR THESE FIGURES~~. TWENTY MILLION AMERICANS ARE IN NEED OF MENTAL HEALTH CARE RIGHT NOW -- ROUGHLY 10 PERCENT OF THE POPULATION; WHEREAS JUST OVER A MILLION AMERICANS DIED OF HEART ATTACKS LAST YEAR AND MORE THAN 350,000 DIED OF CANCER.

SO IT IS NOT THAT MENTAL ILLNESS IS LESS PREVALENT THAN OTHER MAJOR DISEASES; IT IS THAT MENTAL ILLNESS IS SIMPLY NOT AN ACCEPTABLE CONDITION PEOPLE WANT TO TALK ABOUT OR DEAL WITH.

AND WE ALL KNOW THIS STATE EXISTS BECAUSE OF THE MISCONCEPTIONS THAT PREVAIL.

WE MUST WORK HARDER TO REPLACE EACH MYTH ABOUT MENTAL ILLNESS WITH A REASSURING TRUTH.

WE MUST STOP OVER-INTELLECTUALIZING, STOP WORRYING ABOUT OUR JARGON, AND SPEAK IN SIMPLE, DIRECT LANGUAGE THAT PEOPLE CAN UNDERSTAND.

LET ME TELL YOU HOW A STATE SENATOR FROM NEW JERSEY SUGGESTED TO ME THAT WE APPROACH THE ISSUE. HE SAID, THAT IN THE UNITED STATES WE NEED TO TRY TO CREATE A NATIONAL COMMITMENT, A NATIONAL ATTITUDE, A NATIONAL CLIMATE FOR THE PROPER CARE AND TREATMENT OF THE MENTALLY ILL. BECAUSE IF WE DO THIS, HE SAYS, THE REST -- THE LAWS, THE GOVERNMENTAL REORGANIZATIONS THE FUNDING, THE SERVICES -- ALL WILL FALL NATURALLY INTO PLACE.

I BELIEVE THAT.

AND I BELIEVE THAT IS A MESSAGE WITH GLOBAL SIGNIFICANCE.

THOSE OF US AROUND THE WORLD -- IN DEVELOPING AND DEVELOPED NATIONS -- MUST COMMIT OURSELVES TO THE CREATION OF A CARING SOCIETY WITH GLOBAL BONDS.

WE MUST CREATE A CLIMATE IN WHICH OUR MOST VULNERABLE ARE ACCEPTED.

WE MUST START FIRST WITH THEM.

THEN THE REST WILL FALL NATURALLY INTO PLACE.

This was the first time, but not the last, that we would hear as a Commission of the pain and the difficulties that former mental patients encounter firsthand in our society -- in finding a decent place to live, in securing employment, in every kind of social situation. On this point, I would like to emphasize that when Jimmy speaks of human rights, he refers not only to political, and religious and racial oppression, but of the rights of former mental patients, the elderly -- of everyone -- to lead a dignified life. He is calling for ~~speaks of the need~~ for a caring, humane society, world-wide.

The extent to which people who ~~are having, or~~ have had emotional problems are prevented from leading satisfying, dignified lives ~~was~~ --indeed, who instead are subjected to everything from ~~was~~ brought home to me, and to the Commission, many times during the spring and summer as we conducted ~~6666~~ public hearings in four American cities: Philadelphia, Nashville, Tucson and San Francisco. We talked to hundreds of people, we listened to hundreds of people, and it was clear that The stigma of mental illness ~~has~~ is indeed a thing of the past ~~only~~ not ~~come out of the closet~~, as Mr. Watts and Ms. Allen pointed out; it pervades every level of endeavor in this country. Let me share with you some of the remarkably candid, and really very helpful poignant statements made at these public hearings, ~~and~~ I know I don't need to remind you that they do not come out of the Dark Ages -- these statements ~~they~~ were made in four englightened and progressive American cities just a few weeks ago.

and his personal representative on the Commission.

I would be a truly active Honorary Chairperson. So we were off to a good, serious, flying start.

A fascinating aspect of that first Commission meeting in March was that every priority mental health problem that came up surfaced seemed to be related in some way -- directly or indirectly -- to the basic barrier of stigma.

From the outset, stigma was seen as the real enemy. A particular portion of the dialogue of that first meeting still stands out in my mind. Glenn Watts, the President of the Communications Workers of America -- and one of our Commissioners -- ~~was stressing that the cost of effective mental health care was also acknowledged as a barrier standing between the 20 million people in this country who need mental health care and their willingness and ability to seek it,~~ said this: "Mental illness is not understood or accepted by the public. It has been said that it has come out of the closet, but I simply do not believe this. If it had, ~~if there really was no stigma~~, we would be getting the needed appropriations of funds for mental health research and services from the federal, state and local governments. And we aren't getting them. And little can happen until public attitudes change."

Then another new Commissioner, Priscilla Allen, a former mental patient, spoke up and said "I am half in the closet and half out. I am a former patient, and I intended to have everyone on the Commission know that; but I did not want to announce it to the United States of America. With the press here, it was really difficult for me to identify myself. There is definitely a great deal of stigma attached to mental illness. I have been all over the United States -- Florida, Pennslyvania, and I live in California -- talking about mental health issues and about patients' rights issues. But the people in the place where I live do not know, most

of them, that I am a former patient. I didn't tell the manager this when I filled out the form. When I told him later, he said he was glad he hadn't known because he would not have let me in."

In one study Priscilla told us about, an effort was made to educate the public about mental illness. After this education effort, a survey discovered the attitudes of the community had dropped, and their prejudices were worse than before.

page 3---add

In many communities in my countrya, sponsors of group homes have been forced to go to court and file suits when local zoning appeals boards have refused occupancy permits. Im Massachusetts, New York, New Jersey and California, however, judges have ruled that group homes can be established.

Clearly, we must stop, etc.etc...

page 5 -----add

The Institute for Social Research at the University of Michigan has just released research showing how Americans view their mental health. They have discovered that among people who seek help, more than 70% do not go to mental health professionals.

The single most important reason for not getting care is because people feel they should solve their problems themselves.

The second reason they stay away is because of over-riding feelings of shame. And, significantly, this shame is twice as compelling as cost.

And please listen to this: the Michigan study shows that stigma is perceived as a bigger problem now than it was twenty years ago!