Expert Testimony Before the Policy Committee of the 2005 White House Conference on Aging

January 24, 2005

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2005 White House
Conference on Aging

Testimony of Robert Bernstein, Ph.D.
To the Policy Committee
Of the White House Conference on Aging
January 24, 2005

My name is Robert Bernstein, executive director of the Bazelon Center for Mental Health Law and a member of the executive committee of the National Coalition on Mental Health and Aging. Our coalition was established more than a dozen years ago for various organizations with interests in older adulthood to exchange ideas and collaborate on strategies that support the mental health. The coalition now consists of more than fifty groups, including consumer and professional organizations, advocacy groups and representatives from government agencies.

It should not be surprising that concerns about mental health and aging have fostered a large coalition reflecting very broad constituencies. As the policy committee is well aware, older adults are a large, diverse and growing population, including several generations of Americans. Individuals with mental health needs are represented in each of these aging cohorts. Many have persistent, so-called "serious" mental illnesses and are aging as the longstanding clients of public systems. They are challenged by psychiatric disability, age-related health issues and their marginalized social status as "former mental patients." Also included are older adults with later-onset mental illnesses, whose issues of depression and anxiety are often undiagnosed or misdiagnosed —this despite the fact that such mental health problems may be associated with as many as 70% of all primary care visits. And among each of these subpopulations, a substantial number of individuals have co-existing problems of medication or alcohol abuse.

Common to all of these groups, and of common concern to members of our broad coalition, are issues of *access* —perhaps of even greater concern than issues of technical know-how. Current policies and practices too often prevent older adults with mental illnesses from remaining in their homes, with their families, in their communities and participating fully in everyday life. Bluntly stated, we know how to help older adults with mental health needs; the nation has simply not committed to doing it.

The consequences of our failure to provide the services and supports needed by these older Americans are felt by many beyond those who bear the clinical diagnoses. Our failure to address issues of mental health and aging appropriately deeply affects spouses —themselves often elderly—who provide caregiving that prevents or forestalls institutional placement. It affects middle-age people caught between working, parenting obligations and attending to the needs of their own parents. It concerns taxpayers because precious healthcare dollars are being imprudently used to respond to the late-stage consequences of neglect rather than to reduce the impact of mental disability in the first place. And our failure is seen as tragic by any American who cares about compassionate treatment of older adults.

Ironically, given the enormity of the problem and its broad reach, mental health and aging has a long history of being the second- or third-rung priority in several sectors — even,

shamefully, in mental health systems. For this reason, and in recognition of the important opportunity presented by the White House Conference on Aging, the National Coalition on Mental Health and Aging has developed a set of consensus recommendations for action. We will highlight many of them for you today.

Our recommendations draw on the extensive background of our diverse membership. They build on and reinforce findings of the Surgeon General who, in his 1999 report on mental health, identified mental illness among older Americans as a major public health issue and cited our failure to connect people with effective services and our need to expand our knowledge base. Our recommendations to this committee, many of which will be presented by individuals personally affected by the unmet mental health needs of older Americans, will also include problems that are artifacts of public policy, such as the dilemma of older adults who are dually eligible for Medicare and Medicaid, yet who still encounter problems in coverage for their psychotropic medications.

Our recommendations fully support those of the President's New Freedom Commission on Mental Health, particularly the honest finding that the service delivery system is fragmented, "in shambles," and in need of a transforming overhaul. The Commission calls for a new benchmark of mental health outcomes that embraces concepts that are central to mental health, yet are today disgracefully rare in the provision of services; recovery and hope. While these findings by the President's Commission apply to all people with mental illnesses, older adults arguably have been particularly ill-served and systematically deprived of hope and opportunity. Likewise, notwithstanding the landmark1999 *Olmstead* decision by the Supreme Court, finding that unwarranted institutionalization is a form of discrimination that reinforces the notion that institutionalized people are unworthy or incapable of community membership, older adults continue to be unnecessarily consigned to institutions that segregate them from their families and their communities. But the good news is this: We know how to help older Americans who have mental illnesses. What we need to overcome are problems in early identification of mental health needs, the present lack of access to services and supports that are effective and acceptable for older adults, and our failure as a nation to properly prioritize mental health and aging. Our hope is that the testimony you will hear from several of our members and the action steps we recommend will assist this White House Conference on Aging in giving mental health the priority it merits.

Testimony of Laurie M. Young, Ph.D.
To the Policy Committee
Of the White House Conference on Aging
Consumer Perspective of Mental Health and Substance Abuse Key Issues
January 24, 2005

I'm Laura Young, executive director of the Older Women's League and a member of the National Coalition on Mental Health and Aging. I want to thank you for the opportunity this morning to speak with you about the prevalence of mental health disorders in our aging population, the consequences of inadequate treatment, as well as the consequences to informal primary caregivers who care for them. I come to you today wearing multiple hats. I am a consumer of mental health services, a provider of mental health services, as well as an national advocate who served as the primary caregiver to an aging parent with mental health disorders. All of the groups I represent before you are challenged by an inadequate system of care and a need for a more comprehensive public policy regarding mental health and aging over the next decade.

Most Americans think that mental illness is a normal part of aging. Many think, "I'd be depressed too, if I were getting older." In fact, mental illness, dementia, and substance abuse are not a normal part of aging. Most older adults continue to grow, thrive and enjoy life as they age. They live long years without mental illness. This is not the case for many other older Americans. In fact:

- One in five Americans—young and old and in-between—has a diagnosable mental disorder during any one-year period (National Institute of Mental Health/NIMH).

- The most common mental disorders for adults aged 55 and older are anxiety, mood disorders, and severe cognitive impairment (American Association for Geriatric Psychiatry/AAGP).

- Out of 35 million older Americans, two million are estimated to have a diagnosable depressive illness, and another five million exhibit significant symptoms of depression (NIMH).

- 11.4% of adults over 55 have an anxiety disorder (NIMH).

We also know that ignoring mental illness is expensive and increases suffering. Research shows that when older persons' physical illnesses are complicated by a mental illness like depression, those patients require more visits to primary care physicians and emergency rooms, greater usage of medications, and more hospital admissions. Also, their treatment outcomes are worse. For example, rehabilitation from a hip fracture or a heart attack is less successful and more expensive.

Suicide is a huge problem in aging.

- Although adults aged 65 and older comprise only 13% of the U.S. population, they accounted for 18% of the total number of suicides that occurred in 2000 (NIMH).

- The highest rate of suicide (19.4 per 1,000) is among people aged 85 and over, a figure that is twice the overall national rate. The second highest rate (17.7 per 100,000) is among adults aged 75 to 84 (American Association of Suicidology/AAS).

- Older adults have a considerably higher suicide completion rate than other groups. While for all age groups combined there is one suicide for every 20 attempts, there is one suicide for every four attempts among adults who are 65 and older (AAS).

While suicide is the most extreme outcome of inadequate diagnosis and treatment, there are many other consequences to a fragmented system and overlooked illnesses.

- Mental illness among the elderly is routinely under-diagnosed and under-treated; up to 75% of depressed older Americans are not receiving the treatment they need (AAS).

- Only about half of older adults who discuss specific mental health problems with a physician receive any type of treatment. Only a small fraction of those who undergo treatment receive specialty mental health services (AAGP).

- Up to 4/5 of nursing home residents and 2/3 of community residing older adults in need of psychiatric services fail to receive them.

- Medicare covers just 50% of mental health services for older adults (AAGP). While legislation for parity in mental health coverage awaits passage, this will not effect Medicare reimbursement rates for mental health treatment.

- One recent study shows that 80% of older adults recovered from depression after receiving combination treatment of psychotherapy and anti-depressant medication (NIMH)

- Consequences of untreated psychiatric disorders in older people include diminished functioning, substance abuse, poor quality of life, and increased mortality (NIMH).

Undiagnosed and untreated mental illness has serious implications for older adults and their loved ones. Research shows that the sooner people with mental illness get help, the better their long-term outcome will be.

Older Americans, family members, caregivers, neighbors and friends—and especially healthcare providers—need to know the difference between healthy grieving over losses and unhealthy depression, between normal worries and anxiety disorders, and between normal use and overuse of alcohol and medications to dull emotional and/or physical pain.

Failure to provide adequate mental health care for older adults takes a disproportionate toll on women. Consider one common illness: depression. Women are more than twice as likely as men to be diagnosed with depression and typically live six years longer, further expanding the opportunity for undiagnosed illness. As caregivers, midlife and older women are often left to deal with undiagnosed and untreated mental health disorders in others. Caregivers are at a three times greater risk of depression, especially after caring during a terminal illness.

Several years ago, I found myself a member of the “sandwich generation”, caring for an aging parent with dementia and psychotic depression and a daughter who was then 7 years old. I remember many days walking between them and experiencing the feelings of being pulled in both directions, often worried whether there was enough caregiving to go around. What astonished me

most however, was that despite of my background in mental health, and my then employment as Senior Vice President of the National Mental Health Association, I was constantly frustrated by barriers to treatment for my mother. I fought for a dignity for her during her last stage of life, and found frustration. Lack of information by providers, and overworked and untrained caregivers led to an emotionally tortured end of life experience. Surely there must be a better way. Our older Americans deserve better, and caregivers require public policy that supports their efforts.

Thank you for listening.

Testimony of Mildred M. Reynolds, Ed.D., MSW
To the Policy Committee of the White House Conference on Aging
Consequences of Untreated Mental Health Conditions and Substance Abuse in Older Adults and Benefits of Treatment: A Consumer's Perspective
January 24, 2005

I am Dr. Mildred Reynolds representing the National Depression and Bipolar Support Alliance and am also a Board member of the International Center for Global Aging.

I appreciate the opportunity to speak with you today from the perspective of an Older Adult (I am 74) and as one who has struggled with a mental illness namely, clinical depression much of my life. I know from first hand experience what a difference receiving a proper diagnosis and treatment can make. I am sure that I would not be here today if I had not eventually been treated properly; in fact, I might not even be alive. There were times the mental pain was so great that I just wanted to end my life to escape that pain. Twenty-seven years passed from the time I first sought help until I was given the diagnosis of depression and properly treated with medication. However, it took nine more years of trying various medications before one was developed that worked really well for me.

But am I an exception? Unfortunately, I am not. When my picture appeared in *Parade Magazine* in an article that called depression "America's Hidden Disease," people from over twenty-five states and as far away as Hawaii called me even though my phone number was not published. They were eager to talk to someone who had recovered. But unfortunately, many of them had already tried various treatments and had not found anything that was completely satisfactory. We of the older generation grew up in an era when far less was known about depression and other mental illnesses and there were far fewer treatments available. Furthermore the stigma that surrounded mental illness caused many to not want to seek help. Fortunately, we now know how to diagnose and treat depression effectively so---

Why Should We Be Concerned About The Mental Health of our Older Population?

* Older Americans comprise the most rapidly growing segment of the population with those over 85 the fastest growing of all.
* The Global Burden of Disease Study found that mental illness is the second leading cause of disability and premature death throughout the world. It has been estimated that by 2020 depression will be the second leading cause of disability world-wide.

We of the older generation grew up in an era when far less was known about mental illness and there were far fewer treatments available. But today we are better able to diagnose and have treatments that are effective for most people and most others can be helped. Still many OA do not receive the help they need because their illness is

UNRECOGNIZED and UNREPORTED to their doctor because they do not recognize the symptoms or they are too ashamed to admit they might have a mental illness.

UNDIAGNOSED by professionals. So often common symptoms like sadness are attributed to their many losses and other stresses.

UNTREATED or UNDERTREATED if the dosage is not adequate or it is taken for too short a time.

Consequences of untreated depression include:

* Depression can be fatal. There are more suicides in this country than homicides. Older adults have the highest suicide rate of any age group with persons 85 and older having a rate almost double that of the general population.
* An estimated 17% of older adults misuse and abuse alcohol and medications trying to make themselves feel better.
* Recovery time after surgery or from an illness is longer if one is depressed or has another mental illness.

What We Can Do

* We need to do a better job of educating the public that:
    + Mental illness is a medical illness, not a weakness nor a character flaw.
    + Depression is not a normal part of aging but warrants a correct diagnosis and proper treatment.
    + Effective treatments for depression and other mental illnesses are available.

* We need to train more professionals to work with Older Adults.

* We need additional research so that we can better understand and find ways to treat some illnesses such as Alzheimers and other dementias. I live in a retirement home with 1500 residents and I have witnessed the tragedy of seeing individuals lose their ability to drive, walk, talk and feed themselves or recognize their loved ones. Many of the men of this older generation fought our wars but are left to die alone on wards receiving only custodial care.

* We must not forget the caregivers many of whom are on call round the clock which is conducive to exhaustion, depression and more susceptible to illness.

* Treatment must be AVAILABLE, AFFORDABLE and ACCESSIBLE. The most modern clinic with the best trained professionals will not help if the people who need the services cannot get there. E.g. For me to see my psychiatrist I drive to a subway station, take a train downtown, walk four blocks, and then climb steps to get into the building. What will happen when my arthritis worsens and I can't climb the steps or can no longer drive to the subway station? Furthermore, I am exhausted by the time I get there one and one-half hours later.

* We also must not forget the caregivers many of whom are on call around the clock which can leave one feeling depressed, exhausted or more susceptible to illness.

Our older people who have worked to give us the standard of life that we enjoy today are just as deserving of having their mental illnesses diagnosed and treated as those with physical illnesses.

My journey from the depths of despair at age 30 to the present when at 74 I feel healthier and happier than I have ever been has been a long one. I am reminded of the woman who called me after seeing my picture in *Parade Magazine*. She told me that she had tried everything she knew to do and nothing had worked. She felt so desperate she was contemplating suicide. She explained, "When I got up this morning, I thought today would be my last but when I looked at your picture and saw the smile on your face, it gave me hope." Let us do everything we can to give our older adults with mental illnesses the help they need. For----
With help, there is HOPE.

I know - I've been there!

Testimony of Ira R. Katz, M.D., Ph.D.
To the Policy Committee
Of the White House Conference on Aging
Efficacy of Mental Health Interventions
January 24, 2005

My name is Ira Katz. I am a representative of the American Geriatrics Society to the National Coalition on Mental Health and Aging. I am a Professor of Psychiatry at the University of Pennsylvania and Director of an NIMH-supported Advanced Center for Interventions and Services Research and a VA-supported Mental Illness Research Education and Clinical Center. You have already heard that mental illness is common in late life; that it can be diagnosed as precisely as the other illnesses of late life; that it is a major public health problem in terms of the suffering, disability, and worsening of other medical conditions, and deaths that it causes; and that it is associated with staggering costs for patients, families, and our Nation as a whole. I am here to give an important and optimistic message- treatment works.

The theme that treatment works for the mental disorders of late life has been demonstrated in a growing scientific literature and through its impact on critical documents including the 2003 final report of the President's New Freedom Commission on Mental Health; the 2002 report "Reducing Suicide: A National Imperative" from the Institute of Medicine; the 2001 report "Older Adults and Mental Health: Issues and Opportunities" from the Administration on Aging; the 1999 Surgeon General's Report on Mental Health; and others. Nowhere else is the first goal of the New Freedom Commission, ensuring that "Americans understand that mental health is essential to overall health," as critical as it is in late life. As we use this occasion to take stock of our field, we should celebrate the growth of the evidence base and the fact that we know that treatment works because research works.

It is useful to talk about mental health interventions at multiple levels. At the most basic level are specific elements of treatment such as specific medications or therapies, next are algorithms that provide guidance as to how elements of treatment should be sequenced or combined to optimize outcomes, as well as programs that support the delivery of algorithm-based care, and, finally, there are the policies that can be facilitators or barriers of care. Here, our goal is to work toward ensuring that evolving policy is informed by knowledge of the effectiveness of mental health interventions in late life.

The largest body of research has been on late life depression where it has led to evidence for the efficacy of antidepressants, as well as psychotherapies including cognitive behavioral therapy, interpersonal therapy, problem solving and others. Treatment has been shown to work for depression, not just in medically healthy older people but in those with illnesses of late life as diverse as Alzheimer's disease, arthritis, cancer, cardiac disease, chronic obstructive pulmonary disease, diabetes, Parkinson's disease, stroke, and others. It works not just in mental health care settings, but also in primary care,

rehabilitation units, home care, and nursing homes. Moreover, research has also shown that treatment works not just to get people well, but to keep them well.
Findings from three large national projects, the NIMH-supported PROSPECT study, the Hartford Foundation-supported IMPACT study, and the VA- and SAMHSA-supported PRISME study have demonstrated that medications and psychotherapy can be incorporated into algorithms and programs that can be delivered to older people in primary care, and that this leads to improved access and outcomes. Moreover, we are beginning to show that the delivery of treatments for depression has effects that go beyond the reduction of depressive symptoms to include associated outcomes such as improved functioning, increased control of diabetes, reductions in pain related to arthritis, and decreased suicidal ideation.

For Alzheimer's disease and related dementing illnesses, there is evidence for a real but modest effect of medications in improving cognitive performance, as well as a robust effect of caregiver-centered treatment and support groups in delaying nursing home placement. There is also evidence that treatment works for the psychoses, depressions, and behavioral symptoms that occur as components or complications of dementia for most patients with Alzheimer's disease. Atypical antipsychotic medications have positive effects on behavioral symptoms such as agitation and aggression, and serotonin uptake inhibitors have benefits for the depression of Alzheimer's disease. There is also evidence for effects of specific activities, behavioral treatment, and environmental interventions for behavioral symptoms, especially in nursing homes, and for the benefits of caregiver-mediated behavioral treatment for the depression of Alzheimer's disease.

We know somewhat less about effective treatments for anxiety disorders in the elderly, but the emerging literature appears to confirm the effectiveness of both medications and specific psychotherapies. There is also need for more research about the treatment of the serious mental illnesses such as schizophrenia and bipolar disease that can begin in young adulthood and persist into old age; here the ongoing focus is on both the manner with which pharmacological treatments should change as the brain and body age as well as on opportunities for rehabilitation, even in late life.

In reviewing the outcomes of interventions, it is also important to acknowledge that elderly people, especially individuals with significant psychiatric-medical comorbidity, are those who are most vulnerable to side effects from medications, and that certain side effects may occur specifically in older people. Recent findings include the risks of cerebrovascular events from atypical antipsychotic medications in nursing home residents and risks of both falls and bleeding from serotonin reuptake inhibitors. Thus, delivering treatment to older people must require careful evaluation of benefits versus risks, close monitoring of outcomes, and expertise about the process of aging and the diseases of both the body and mind that all too often accompany it.

What are the policy issues that should follow from the evidence for the effectiveness of our interventions for the mental disorders of late life?

First and foremost, Medicare and Medicaid policies should make these treatments available to all of those in need. The basic payment and training issues will be discussed by others. However, I would like to mention some policy related issues that follow directly from the findings discussed here.

With the current evidence for the effectiveness of programs integrating mental health with primary care, Medicare policy should include payment for care management programs to support a role for primary care providers in collaboration with mental health professionals in managing the mental disorders in late life.

With respect to medications, there is a need to recognize the unique issues of older individuals with a more stringent geriatric rule for the FDA for the testing of new medications in old people; increased post-marketing surveillance for side effects of medications in the elderly; and attention to the facts of aging and the resulting drug-drug and drug-disease interactions in developing the Medicare formulary and Part D policies.

With respect to psychotherapy, recognizing that compelling evidence for the effectiveness of specific therapies has developed in parallel with evidence for the side effects as well as the benefits of psychiatric medications should lead to a reevaluation of Medicare payment policies for psychotherapy. The value of reevaluating payment for psychotherapy is strengthened by the changing pattern of the costs of care related to the implementation of Medicare Part D.

Finally, it is important to acknowledge the engine that has driven much of the research we have discussed, the Aging Branch of the extramural research program at NIMH. There should be ongoing recognition and support of this Branch as a critical component of the overall Federal investment in Aging research.

Testimony of Kristen Lawton Barry, Ph.D.
To the Policy Committee
Of the White House Conference on Aging
Efficacy of Substance Abuse Interventions
January 24, 2005

I have been invited by the National Coalition on Mental Health and Aging to speak with you about the efficacy of substance abuse interventions. I am a Research Associate Professor with the University of Michigan Department of Psychiatry.

An estimated 17% of older adults have problems related to their use or misuse of alcohol and medications such as benzodiazepines and sedative/hypnotics, the majority of whom do not meet DSM-IV criteria for abuse/dependence. In addition, an even larger percentage of the population of aging 'Baby Boomers' is expected to have problems related to alcohol and illegal drug use. The majority of older adults experiencing these problems do not recognize that their misuse of alcohol or medications/drugs is putting them at risk for further medical and mental health problems.

The comorbidity of mental illness and substance abuse exacerbates symptoms and often leads to treatment noncompliance, more frequent hospitalization, greater depression and potential for suicide, family friction, and higher service use and cost (DHHS, 1999).

There is a body of research showing that brief interventions and brief therapies are effective in helping at-risk older adults to cut down or stop using alcohol and to stop misusing medications. Brief interventions and brief therapies that use motivational interviewing principles and a supportive, nonjudgmental approach have been shown to be particularly effective with older adults. The SAMHSA Center for Substance Abuse Treatment (CSAT) Treatment Improvement Protocol #26 on older adults recommended that the least intensive options be explored first for older adults having problems related to substance use. When more specialized treatments are needed, age-specific approaches have been shown to be most effective, but regardless of the formal treatment program, studies have shown that older adults are significantly more likely to complete treatment than younger adults, one of the markers affecting longer-term outcomes.

There are also key areas for future work in this field in terms of research and training. There remains a need to conduct research to determine the best-practice approaches to intervention and treatment for various segments of the aging population. Finally, it is important to bridge the gap between research and practice through a state-of-the-art training directed to the broad base of health care providers who work with this vulnerable population of older adults.

Testimony of Linda Powell
To the Policy Committee
Of the White House Conference on Aging
A Consumer's Perspective of Barriers to Mental Health and Substance Abuse Services and Solutions
January 24, 2005

My name is Linda Powell. I am a representative of the Older Adult Consumer Mental Health Alliance (OACMHA) to the National Coalition on Mental Health and Aging. I am a long time mental health consumer advocate having served as OACMHA's first Executive Director. OACMHA is the only national consumer run advocacy organization working on behalf of older adults with mental illness.

I am also the primary caregiver for my 84-year-old father who is disabled due a stroke, has dementia and suffers greatly from depression. I know first hand the problems faced by millions of other Americans who are trying to find services that will address the mental health needs of their older loved ones.

The stigma of seeking traditional mental health services is overwhelming for many of today's older adults. We have to remember, this is a strong, proud generation that pulled this country through a depression and a "war to end all wars". They were taught to do for themselves and not look to others for help. Now so many of them face a battle they cannot win by themselves and this is often a bitter pill to swallow. For that reason, a national anti-stigma campaign must be launched and include a special emphasis on reaching older adults will mental and cognitive disorders. Too often in America, the media portray older adults as those having a great afternoon on the golf course or those tied to chairs in long term care facilities. The lives of those who struggle with mental disorders but are somehow able to find services and begin the work of recovery are seldom portrayed on television or in the movies. A strong, national anti-stigma campaign that brought together organizations like those represented here today, with media savvy professionals could make a huge difference in the lives of many people across the country.

These remarkable people, who really formed the backbone of this country, should be revered and seen as national treasures and respected elders, but when it comes to mental health issues they are invisible to far too many. If mental health services and issues for older adults are not designated as a priority for the public mental health and substance abuse system and the White House Conference on Aging this group will once more be pushed aside. Children gained this status many years ago, it is now long overdue for older adults to benefit from this designation.

You have read the statistics, 20% of older adults suffer from some debilitating form of mental or cognitive disorder. Older adults have the highest suicide rate of any age group. To me this is just unacceptable. I fight the fight every day to keep my father engaged in life, but it is a battle that takes it toll on my family and me just as it does on millions of other families across this country. I have been a mental health advocate for many years. I know how to work the system and still I struggle. Think about those people who have never had to advocate for

anything before. It is a daunting task. Add the stigma of mental illness to all that and many people just give up.

Please don't give up on these people and their families. Make mental health and substance abuse concerns a top priority for the 2005 White House Conference on Aging.

Thank you.

Testimony of Willard Mays, MA
To the Policy Committee
Of the White House Conference on Aging
Financing Barriers and Solutions
January 24, 2005

My name is Willard Mays. I represent the National Association of State Mental Health Program Directors and the American Society on Aging on the National Coalition on Mental Health and Aging and am the immediate past chair of the Coalition. I am the Assistant Deputy Director for Public Policy for the state mental health authority in Indiana.

Unfortunately many current and proposed federal policies create significant barriers in moving mental health and substance abuse promising and evidence-based practices from research to actual provision of services to older adults. This is particularly true of the Medicare and Medicaid programs. Medicaid is by far the largest payer of institutional care of older adults with mental illnesses. Although, according to the Centers for Medicare and Medicaid Services (CMS), almost one-quarter of the nation's Medicaid budget in 1998 went to support nursing home care, numerous studies have found that the mental health needs of residents remain under-addressed and often unrecognized. The majority of the services provided are neither the result of assessments by, nor directly provided by, qualified mental health professionals. A 1999 DHHS report found that Medicaid funding policies actually discourage the provision of specialty mental health services in nursing homes.

While nursing home care is a mandated Medicaid service the provision of community-based mental health care is not and results in states having to navigate through a maze of options and waivers. The Institutions for Mental Diseases restrictions and the fluctuating level of care of persons with mental illness make it virtually impossible to develop a Home and Community-Based Services (HCBS) Waiver. At present only one state has a mental health specific waiver for persons over the age of 21. The basic problem, the cost neutrality requirement, could be addressed by comparing the annualized Medicaid cost of serving the individual in any setting, rather than an institutional setting, with the cost of serving the person through a waiver.

Medicare coverage of mental health services, including both institutional and community-based care' is also minimal. Although Medicare is the largest funding source for health care of older adults only slightly more than one half of one percent (0.57 %) of total Medicare expenditures are for mental health services (Bartels and Smyer, 2002), and less than one-half of one percent of expenditures are for non-institutionalized recipients (Colenda et al., 2002).

Those individuals that are eligible for both Medicare and Medicaid, known as "dual eligibles", represent another major problem. The complexity in coordination of benefits and inadequate reimbursement rates are resulting in providers dropping or reducing mental health services to these individuals. In Indiana I am aware of three mental health

providers that have either dropped their older adult practice entirely, or have refused to serve older clients unless they physically come to their office. This is a particular issue for nursing home residents and those who live in rural areas. When this is added to the current and projected shortage of qualified geriatric mental health and substance abuse professionals the word "crisis" is not an exaggeration. A study I did found that 64 of Indiana's 92 counties did not have a psychiatrist, 23 did not have a clinical psychologist while 21 others had only one.

An especially troubling immediate concern is the new Medicare Part D Prescription Drug Benefit. While designed as a way to save seniors money, and to lower government expenditures, on prescription drugs, if not implemented properly, Part D can have a devastating effect on older adults with mental illness. An anticipated way of saving money is allowing Prescription Drug Plans, or "PDPs" to determine what drugs they will provide. The financial incentive would be to include older, less effective, and lower cost mental health drugs and to exclude newer drugs that are more effective, have fewer side effects, but are more costly.

A second problem with Part D is that all "dual eligibles" must enroll in the program and must select a PDP by January 1, 2006 or they will be "randomly assigned". Many older adults with serious mental illness or cognitive impairments, such as Alzheimer's Disease, lack the capacity to make an informed decision and many of those do not have a guardian or health care representative to make a decision on their behalf. As an example let's assume that a nursing facility has 100 residents that are both Medicare and Medicaid recipients. It is likely that some of these residents will not be able to make an independent and informed selection by January 1. As these individuals are randomly assigned it is a real possibility that multiple PDPs will be assigned. Each PDP would likely offer different medications in their packages, which would seriously complicate the mental health care provided by the facility and health professionals serving the residents.

Lack of parity coverage for mental health, as compared to physical health coverage, is an enormous issue, and has not been addressed by Medicare. For example recipients must pay a fifty percent (50%) co-pay for mental health services as compared to a twenty percent (20 %) co-pay for physical health services. While some progress has been made in private sector coverage more attention is needed and the gains accomplished so far, must not be lost.

The current practice of allowing state Medicare carriers to have great latitude in establishing local coverage policy, based on their interpretation of CMS policy, is also a problem. More oversight by CMS is needed to assure consistent nationwide coverage policy.

If these and other issues presented today are to be fully addressed, older adults with mental illness and substance abuse problems must be identified as a priority at the federal level. Federal agencies must coordinate their efforts to maximize the use of available resources. Failure to do so as the population continues to grow through aging "Baby Boomers" and longer life spans, spells an even greater crisis in the years ahead. Action

on these issues at the White House Conference on Aging paired with the recommendations from the President's New Freedom Commission on Mental Health will send a strong message to policy makers across the country. We ask for your support to include these issues on the Conference agenda.

Testimony of Stephen J. Bartels, MD, MS.
To the Policy Committee
Of the White House Conference on Aging
Health Delivery System Barriers and Solutions
January 24, 2005

Chair Person and Members of the White House Conference on Aging Policy Committee

My name is Dr. Stephen Bartels. I am a representative of the American Association for Geriatric Psychiatry and the Geriatric Mental Health Foundation within the National Coalition on Mental Health and Aging. I am also a Professor of Psychiatry at Dartmouth Medical School. In 2002 and 2003 I had the privilege to act as the expert consultant to the Subcommittee on Older Adults for the President's New Freedom Commission on Mental Health. This morning I would like to take several minutes to summarize the findings and recommendations of this subcommittee.

First, a brief summary of findings:

- The mental health system of services for older persons is fragmented across multiple providers and funding streams.

- Access to appropriate and effective services are also complicated by a mismatch between the current system of care and the needs and preferences of older adults. Approximately half of all Medicare and Medicaid mental health funds are dedicated to hospital and nursing homes treatment, though older adults prefer to receive mental health services in home and community based settings.

- Other barriers to access include a required 50% co-payment for psychological services under Medicare; lack of available transportation, and the stigma associated with mental illness and advanced age. As Hikmah Gardiner, an older consumer described to the commission on mental health, if you are old, have a mental illness, and also are African American, you face a triple stigma.

- Older persons are more likely to receive inadequate, inappropriate, or no mental health care at all, compared to younger persons.

- Despite considerable research findings clearly demonstrating that there are effective treatments for late life mental disorders, there is a profound gap between research findings on effective treatments for mental disorders in older adults, and the quality of clinical practice in usual care settings.

- Current problems in the quality of mental health services in the community are only likely to worsen in the future due to an underinvestment in research on late life mental disorders.

- The critical role of prevention has been neglected, as illustrated by the fact that older adults have the highest suicide rate of any age group, despite most making a visit to their primary care physician in the week prior to committing suicide.

- Finally, there is a dramatic shortfall in a trained workforce to address the mental health needs of an aging America.

Three major areas were identified for policy recommendations and reforms:
(1) access, (2) quality of services, and (3) workforce and caregiver capacity.

1) Improve Access and Continuity of Care

- There is compelling evidence supporting the effectiveness of integrated mental health services in primary care. There are also multiple studies supporting the effectiveness of multidisciplinary outreach services in identifying and providing treatment of older adults with mental health problems in the community.

- A primary recommendation from the President's Commission is for CMS to revise payments to support integrated mental health services in primary care by allowing same day medical and mental health procedures.

- In addition, appropriate mechanisms should be developed to provide reimbursement for multidisciplinary mental health outreach teams providing assessment and treatment services in home and community-base settings.

- Care management should be promoted by CMS and appropriately reimbursed to coordinate services for older adults with mental disorders across different service providers, agencies, and settings.

- Medicare mental health parity legislation should be passed to eliminate the discriminatory 50% co-payments under Medicare for psychological services.

- The growing gap between mental health provider costs and rates of payments needs to be addressed by adjusting the Medicare rate structure if we are to stem the tide of providers declining treat Medicare beneficiaries.

- Finally, barriers to mental health services due to stigma need to be addressed by a national campaign by HHS, AoA, and other appropriate agencies promoting public and professional awareness that mental disorders in older adults are a public health problem that can be prevented and treated.

2) Improve Quality of Mental Health Services for Older Adults

- A national initiative should be supported by SAMHSA, NIMH, AoA, and CMS to disseminate and implement geriatric evidence-based mental health practices in routine service delivery settings including aging network, long-term care, primary

care, and settings where older adults seek and receive services.

- An increase in funding to NIMH, NIA and other federally supported research agencies is needed for research on the causes and treatments of mental illness in older adults if we are to address the public health challenge of prevalent mental health problems in an aging America.

- Mental health, substance abuse, and cognitive screening and prevention programs for older persons should be promoted by the CMS, CDC, SAMHSA, and NIH, and should be reimbursed by private health insurance programs and Medicare.

- Finally, CMS should promote consumer preferences and shared decision making in shaping the goals of mental health treatment.

3) Improve Workforce Capacity and Caregiver Support

I will address recommendations for improving the professional workforce capacity in a later panel. However a vital component of the workforce that is commonly neglected are caregivers who are often family members of the older person with a mental disorder.

- Family caregiver support interventions have been proven to be effective in preventing unnecessary nursing home placement of persons with mental disorders and in preventing disabling depression in the caregiver. CMS should be directed to develop codes that support evidence-based caregiver support interventions that are currently not covered by Medicare or Medicaid.

- There is a need for promoting partnership between federal programs and advocacy organizations and directing state and county health systems to support development of peer support programs specifically for older persons

In closing, we strongly encourage that the final recommendations of the White House Conference on Aging explicitly embrace the principle that mental health is vital to physical health, and that quality mental health services are essential to effective health care and health promotion. The work of the Older Adult Subcommittee of the Older President's Commission on Mental Health provides a valuable summary of specific approaches to improving access, quality and workforce capacity in order to address the current and growing needs of older adults with mental health needs in America.

I would like to thank the committee for the opportunity to testify here today and I will be happy to answer any questions.

Testimony of Alixe McNeill, MPA
To the Policy Committee
Of the White House Conference on Aging
The Role of Community-based Organizations in Connecting Older Adults to Mental Health and Substance Abuse Services
January 24, 2005

I am Alixe McNeill, the The National Council on the Aging Representative to The National Coalition on Mental Health & Aging. I will address the role of community-based organizations in connecting older adults to effective mental health and substance abuse services.

Older people need to gain access to prevention, screening, and treatment through the organizations and services they use. The integration of older adult mental health and substance abuse services into community-based service systems, primary health care, and long-term care will break down barriers of stigma and encourage older adults to gain the help they need to maintain mental health.

The aging services network is tremendous resource of more than 29,000 community-based agencies serving close to 10 million older people each year. These senior centers, area agencies on aging, case management services, day services, in-home care programs, and many others have the reach and confidence of older people.

The aging services network has long been a champion of home and community-based services as an alternative to institutionalization for many older persons. NCOA and many others continue to identify, shape and support a variety of public and private funding mechanisms for these critical services. We trust the White House Conference on Aging will make this a priority.

Many of the aging service organizations have the mission, capacity and interest to find and serve isolated older people as well as those who show-up for health fairs, group meals, education sessions and other programs. Many offer culturally competent prevention and education programs. Some conduct evidence-based screening for mental health problems, alcohol and medication misuse and abuse. A few offer evidence-based treatment in collaboration specialists. Many refer older people and caregivers to mental health and substance abuse specialists, follow-up and support people during and after treatment

We know there is a lack of adequate preventive interventions and programs to aid in the identification and treatment of geriatric mental illness and substance abuse; many more organizations in the aging services network are open to offering these services in collaboration with specialists. For example, in the last year more than 9,500 organizations ordered the Substance Abuse and Mental Health Services Administration (SAMHSA) - NCOA “Get Connected” Toolkit for aging service organizations to educate, screen, and link older adults to the mental health and substance abuse resources they need.

Through a recent survey of senior centers, NCOA and AoA is learning that many senior centers have the capacity and willingness to implement evidence-based programs that promote fitness and health and decrease depression, but centers lack the modest funding needed. Aging services leaders want to concentrate limited resources on proven programs. They continually seek information on evidence-based, promising and best practices.

Community-based organizations are helping to move research to service delivery. One successful example is the work of the AoA Evidence-based Prevention Programs, a public/private partnership to increase access for older people to programs that have proven to be effective in reducing the risk of disease, injury, and disability. Federal agencies and private foundations are coordinating their efforts to help implement evidence-based prevention including mental health and medication management programs through local aging services providers. Some models imbed effective practices into on-going case management services without needing to add new staff. This program and others translating research into service need continued support. Additional funding will be needed to take these proven interventions to scale nationwide.

These recommendations would be further advanced through legislation like the Positive Aging Act of 2004 introduced in the US Senate and House with bi-partisan support. This Act, also supported by NCOA and many other members of the Coalition, would improve the accessibility and quality of mental health services for older Americans. The Act called for authorizing the Administration on Aging (AOA) and the Substance Abuse and Mental Health Services Administration (SAMHSA) to fund projects that integrate mental health screening and treatment services at community sites and primary health care settings including senior centers, naturally occurring retirement centers (NORCs), community health centers, and assisted living facilities.

The National Coalition on Mental Health and Aging recommends that the White House Conference on Aging support efforts to increase the effective use of resources and reduce fragmentation through increased collaboration among aging, health, mental health and substance abuse organizations, government agencies, and academic institutions.

Thank you for your kind attention.

Testimony of Anita L. Rosen, Ph.D.
To the Policy Committee
Of the White House Conference on Aging
The Shortage of an Adequately Trained Geriatric Mental Health Workforce
January 24, 2005

I am Anita Rosen, the American Society on Aging and Council on Social Work Education representative to the National Coalition on Mental Health and Aging. Thank you for the opportunity to address you today about the critical shortage of adequately trained geriatric mental health and substance abuse practitioners.

You have already been presented with information about the consequences of untreated mental health conditions and substance abuse, the benefits and efficacy of treatment, and the barriers to treatment. One major barrier to treatment is the current workforce crisis in mental health and aging. There is a serious shortage of mental health professionals with adequate training to meet the mental health, substance abuse and psychosocial needs of a growing aging population and their family caregivers. Numerous studies, including the President's own New Freedom Commission (July, 2003) clearly state that there is a "severe shortage" of practitioners in the mental health workforce, including those who can provide services to adults and older adults. There is a workforce crisis now with 12.4% of the population age 65 or over; by the year 2030 when the entire Baby Boomer population will be over age 65, older adults will comprise 20% of the population (AoA, 2005).

The shortage of trained geriatric mental health practitioners is a problem among ***all*** mental health professions and is particularly acute in rural areas. The current situation means that treatable mental health and substance abuse problems of older adults often go untreated or they are treated ineffectively or inefficiently. This lack of adequate and available workforce has been shown to be costly to individuals, families and society.

There are a variety of factors that have created this problem, many of which have been or will be discussed by others today. They include a lack of parity in reimbursement that makes mental health and aging practice less desirable than other areas of practice, lack of traineeships and student stipends for the mental health professions, and lack of academic efforts to teach aging content to all mental health professionals.

The severity of the workforce crisis can be illustrated with a sampling of data provided for this presentation by several of the mental health professional groups that are members of the National Coalition on Mental Health and Aging.

Social Work: As of 2002, only about 1,115 or 3.6 % of Master's level social worker students specialize in aging and only about 5% of practitioners at any level identify aging as their primary area of practice (Lennon, 2004). This is true even though the National Institute on Aging projected that by 2020, 60,000-70,000 gerontological social workers will be needed (NIA, 1987).

Psychology: Among psychologists, only about 3% view geriatrics as their primary area of practice and only 28 % of all graduate psychologists have some graduate training in geriatrics. This falls short of the current need for 5,000 to 7,000 FTE geriatric psychologists (Qualls, et. al., 2002).

Mental Health Nursing: Data on nursing suggests that few nurses specialize in mental health and aging, since less than 1 percent of all nurses even identify mental health or substance abuse facilities as their primary area of practice, and these settings are not typically used by older adults with mental health or substance abuse problems (Communication with Rita Munley Gallagher, ANA, 1-12-05).

Psychiatry: The current workforce of geriatric psychiatrists is 2,595 practitioners of a total of 38,691 psychiatrists. By 2006, that number is expected to by reduced 23%. In fact, at the current rate of graduating approximately 80 new geriatric psychiatrists each year, and given attrition, there will be one geriatric psychiatrist per 5,682 older adults with a psychiatric disorder by the year 2030 (Communication with Stephanie Reed, AAGP, 1-13-05).

Compounding the current problem of a workforce crisis in mental health and aging, is the fact that a substantial percentage of all mental health professionals who do work in aging are Baby Boomers and will be retiring or reducing their work loads in the near future. We have a shortage now, but who will replace these Boomers, who often went to school at a time when there were stipends, special curriculum and training projects, and other support?

Additionally, many of the projections of need for mental health and aging professionals are based on current service needs. The current cohort of older persons may differ from Baby Boomers in regard to lifestyle choices and mental health or substance abuse issues. For example, Baby Boomers have made use of mental health services in appreciably larger numbers than people over age 65 today and have experienced a much greater use of recreational drugs (Korper & Council, 2002). They also reflect increasing diversity of the U.S. population. These differences alone suggest that the aging of Baby Boomers may create an even greater demand for services of trained geriatric mental health professionals in the future.

Is it possible that the workforce crisis described is somewhat exaggerated? In fact, the crisis may be worse than the numbers indicate. Unlike many other areas of mental health and substance abuse training, most non-geriatric specialists are provided little in the way of exposure to aging practice in either the classroom or in field practica (AFAR, February 2002), yet they may be called upon to provide services to older adults. For example, Peterson and Wendt (1990) found that 62% of social work practitioners had need for aging knowledge in their practice even though aging was not their primary field of practice.

There is little evidence to indicate that mental health students have even minimal exposure to gerontological content in their foundation course work or in field practica, or have been provided with positive and interdisciplinary educational opportunities to interest them in work with older adults and their families. Mental health professionals also have need to address the multiplicity of mental health, health, social, economic and housing issues to work effectively with older adults and their families (Zeiss & Steffon, 1996); yet professional mental health

education programs rarely provide effective interdisciplinary team training. Only a limited number of practitioners have taken courses through HRSA supported Geriatric Education Centers or have had opportunity to train through the John A. Hartford Foundation Geriatric Interdisciplinary Team Training projects (Scharlach, Damron-Rodriguez, Robinson, & Feldman (2000). Most must rely on their academic preparation to provide these basic competencies, but few mental health academic programs have the resources or incentives to provide these skills.

The current mental health and aging workforce crisis is compounded by the lack of a concerted effort to prepare ***all*** students with basic aging competency and provide ***all*** current mental health practitioners with basic knowledge and skills to more effectively meet the needs of older adults, including grandparents raising grandchildren and family caregivers (Communication with Rita Gallagher, ANA; AFAR, February 2002; Rosen, Zlotnik, & Singer, 2002).

As indicated by the President's New Freedom Commission, it is imperative to quickly develop a strategy to effectively address the critical need for trained mental health and substance abuse professionals with aging competency. The two presentations that follow will give some substantive recommendations for addressing the severe shortage of professionals with mental health and aging competency. We hope that these recommendations will be considered seriously for inclusion in the 2005 White House Conference on Aging

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Testimony of Stephen J. Bartels, MD, MS.
To the Policy Committee
Of the White House Conference on Aging
Recommendations for Addressing the Shortage of Geriatric Mental Health Professionals
January 24, 2005

Chair Person and Members of the White House Conference on Aging Policy Committee

My name is Dr. Stephen Bartels. I am a representative of the American Association for Geriatric Psychiatry to the National Coalition on Mental Health and Aging. I am Dr. Stephen Bartels, Professor of Psychiatry at Dartmouth Medical School. I am here today to convey the serious concerns shared by the National Council on Mental Health and Aging, researchers, clinicians, and consumers that the current number of healthcare providers is inadequate to meet the needs of older persons with mental illness.

The shortage of healthcare providers with geriatric training is expected to grow as the population of older Americans increases over the coming decades. The healthcare workforce is unprepared to address the growing number of older adults with mental health problems.

- Approximately 2,500 psychiatrists have received added qualifications in geriatric psychiatry, yet 4,000 to 5,000 geriatric psychiatrists are needed to provide patient care.

- Primary care physicians provide most treatment for mental health problems among older adults. Yet, the 9,000 physicians with geriatric certification represent less than half of the current need. By 2030, the shortfall of geriatricians may reach 25,000 doctors.

- Only 3% of clinical psychologists devote their practice to serving older adults. While approximately 3,100 FTE psychologists serve older adult, this falls short of the current need for 5,000 to 7,500 FTE geriatric psychologists.

- Less than 1% of registered nurses and advanced practice nurses are certified in geriatric care. Moreover, among the 4,000 members of the American Psychiatric Nurses Association, only 16%, or approximately 640 members, have a sub-specialization in geriatrics.

- Similar severe workforce shortages are also found across other critical healthcare disciplines.

Significant changes are needed to attract healthcare providers into the realm of geriatric medicine. Simply increasing the number of available specialty training positions has not been effective in increasing the number of geriatric providers. Many available training slots in geriatric professions are going unfilled. Moreover, a recent economic analysis actually suggests current rates of reimbursement under Medicare combined with substantial student loan burdens, may make it a losing proposition to pursue advanced training in geriatric medicine and other related professions.

Anticipating the growing demand for geriatric mental health services will require building an adequate infrastructure by training clinicians to provide the services that will be demanded by older consumers with mental health problems. As such, we submit the following

recommendations to address the geriatric mental health workforce shortages, including workforce recruitment, retention, and skills training:

1) Develop incentives and mechanisms to support specialized geriatric mental health training across primary health care, mental health, and social service professions. Key strategies include loan repayment programs, dedicated federal funding for training in geriatric mental health, and designation of geriatric medicine and federal designation of geriatric mental health as an underserved profession.

    - Loan repayment programs are critical to attracting individuals into available training slots and programs in geriatric mental health professions. Examples of loan repayment initiatives include:

        - The Elder Justice Act, reported by the Senate Finance Committee in 2004, contained provisions for training grants to increase the number of health care professionals with geriatric training, including mental health professionals and for loan repayment under the National Health Corps Loan Repayment Program.

        - Legislation has been introduced that would allow each year of fellowship training in geriatric medicine or geriatric psychiatry to be considered a year of obligated service under the National Health Corps Loan Repayment Program.

        These initiatives need to supported and expanded.

    - Dedicated funding is needed to offset the costs of geriatric training as an area that is clearly underserved. Examples of training funding initiatives include:

        - The Graduate Geropsychology Education Initiative of the American Psychological Association has successfully advocated for a separate funding stream for geropsychology education and training in the Graduate Psychology Education Program in the Bureau of Health Professions at HHS.

        - Work continues on an initiative to specify social work as an allied health profession eligible for grants under the health professions training programs administered by the Department of Health and Human Services.

    - Designation of geriatric medicine and mental health as underserved professions in the context of clear population trends requiring dramatic workforce development to meet the public health need.

2) Disparities in reimbursement between geriatric mental health, behavioral health, and substance abuse practice and other areas in health care practice need to be eliminated is we are to attract and retain providers dedicated to mental health and aging.

a. Several initiatives can help address payment disparities for mental health services that constitute major disincentives for mental health professionals to specialize in geriatrics. These include:

    i. Legislation to repeal the discriminatory 50% co-payment required for outpatient mental health services;
    ii. Expansion of opportunities for psychologists to participate in the Graduate Medical Education program;
    iii. Legislation to permit direct payment under Part B of the Medicare program for clinical social worker services provided to residents of skilled nursing facilities;
    iv. Elimination of discretion by Medicare fiscal intermediaries to arbitrarily deny payments for services to persons with Alzheimer's solely because they are submitted by a psychiatrist of other mental health provider, rather than a primary care physician or neurologist.

3) In addition to developing more specialty geriatric mental health providers, training in aging and mental health should be mainstreamed into standard training of health care disciplines. Specific initiatives include:

    a. A requirement that professional mental health and behavioral health education programs that receive federal funding require geriatric course work or rotation for all students on evidence based and emerging best practices and skills in treating older adults with mental disorders;

    b. Encourage states to revise licensing and continuing education requirements so that geriatric mental health, behavioral health, and substance abuse training is required for all licensed health, mental health and social services professionals;

    c. Direct the Department of Health and Human Services to refine its approach to technology transfer in geriatric mental health and behavioral health evidence-based and emerging best practices. This should include development of web-based training curricula, integrated electronic decision support systems, and national initiatives in the dissemination and implementation of evidence-based mental health assessment, treatment and services for older persons with mental health, cognitive, and substance use disorders.

In conclusion, anticipating the growing demand for geriatric mental health services will require building an adequate infrastructure by training clinicians to provide the services that will be demanded by older consumers with mental health problems. This can be accomplished by supporting clinicians who pursue geriatric training, eliminating reimbursement disparities, and supporting training in geriatric health care for all healthcare providers.

I would like to thank the committee for the opportunity to testify here today and I will be happy to answer any questions.

Testimony of Julie Measheey
To the Policy Committee of the White House Conference on Aging
The Need for Mental Health Presence in Long-Term Care
January 24, 2005

My name is Julie Measheey, representing the National Citizens' Coalition for Nursing Home Reform (NCCNHR) to the National Coalition on Mental Health and Aging. I am a Gerontologist working for a national resource center that provides technical assistance to advocates who work with residents of long-term care facilities.

It is a pleasure to be serving on this panel related to the mental health workforce. For 30 years now, the NCCNHR has been highlighting the importance of staff issues in long-term care including staff availability and staff training. In a landmark study conducted in 1985, NCCNHR asked nursing home residents to define a quality long-term care experience.[1] The resident voice was clear. Staff availability (including response to call bells and the provision of needed care) and staff treating them with dignity and respect were more important than anything else in the long-term care experience – more important than cleanliness, more important than activities, and more important than the cost of care.

NCCNHR's experience is that people identify these two factors – staff availability & staff's attitude – whether they are asked to define quality in an assisted living facility or whether they are referring to services they receive in their own home. And, as related to the theme of this listening session, it is imperative that any and all caregiving staff providing long-term care must be adequately equipped to identify and understand mental health needs. In fact, it is the understanding of mental illness and the knowledge of how to interpret behaviors that shapes the attitudes that those in the workforce have towards long-term care residents.

In long-term care, as in all settings, behavior is a method of communication. All people who work with older adults in long-term care (ie. certified nursing assistants, nurses, social workers, general practitioners, etc.) need to know how to interpret behavior and when a behavioral communication may signal a need for mental health services.

Equally important is having access to services and trained mental health professionals who can accurately assess, diagnose, treat, and provide support to those in long-term care who have mental health needs. This expertise is particularly important in this setting because behavioral communication may be a reaction to a care approach rather than a symptom of mental illness. Professionals working in this environment must be especially astute at determining the cause of a behavior so that the solution addresses the underlying need.

In addition to the availability of trained staff, NCCNHR has always maintained that the care planning process (including addressing mental health issues) is essential to quality.

[1] Holder, E. and Frank, B. A Consumer Perspective on Quality Care: The Residents' Point of View. A Project of the National Citizens' Coalition for Nursing Home Reform, 1985.

The aging process involves both physical and psychological change and older adults receiving long-term care are often dealing with an accumulation of losses including a shrinking social support system. Therefore, long-term care must include a thorough assessment and development of a comprehensive plan of care that includes regular re-evaluation. This process should be directed by the person receiving long-term care services and include those providing care.[2]

In generating solutions to address the need for a mental health presence in long-term care, the NCMHA has identified the following suggestions[3]:

We need to assure access to affordable and comprehensive mental health & substance abuse services that include:

- Outreach
- Home and community based care
- Prevention
- Intervention
- Acute care
- Long-term care

And, we need to support the integration of older adult mental health and substance abuse services into long-term care as well as primary health care and community based systems.

Types of needs present in long-term care

The resolutions of the NCMHA are particularly important because older adults who require long-term care services have a high incidence of mental health needs. Depression and dementia are the most commonly seen mental health conditions in this setting, but substance abuse, post traumatic stress disorder, and schizophrenia are also prevalent.

The prevalence of mental health needs in long-term care is extensive.

- The Surgeon General's Report on Mental Health released in 1999, revealed that 20 % of individuals over 55 experience mental illness
- 17% of older adults misuse alcohol, over-the-counter drugs, and prescription medications[4]

[2] Frank, B, Fraser, V, Hunt, S, and Greene Burger, S. Nursing Homes: Getting Good Care There. National Citizens' Coalition for Nursing Home Reform. Second Edition, 2002.
[3] National Committee on Mental Health and Aging. Resolution on Mental Health & Substance Abuse Services and Interventions (Resolutions 1.2.1 and 1.2.7), 2004.
[4] "Promoting Older Adult Health," Resource from Substance Abuse and Mental Health Services Administration Tool Kit (2002).

Approximately 2.8 million older adults reside in nursing homes and adult care facilities.[5]

- Among those who reside in a nursing facility, 65 – 91% of individuals have a significant mental disorder;
- 30 – 40% of those with dementia have significant behavioral & psychiatric symptoms (these include verbalizations such as screaming and behaviors such as wandering, biting, and hitting);
- 22% have symptoms related to depression (weight loss, memory changes, loss of appetite, changes in ability to perform activities of daily living, such as eating, bathing, or dressing); and
- 89% of these individuals will receive mental health care in the nursing home setting rather than a hospital or a mental health facility.[6]

Unrecognized and untreated mental health needs result in greater physical care needs

Despite the documented need for mental health services in long-term care settings, these needs often remain unrecognized and untreated. Why? Because the availability of services to address these needs is at an all time low and too often mental health needs are not adequately assessed in the long-term care setting. A six state survey of almost 900 nursing homes found that psychiatric services are needed for over 1/3 of nursing home residents, yet 3/4 of nursing homes can not access consultation and educational services for behavioral interventions. Access is particularly poor in rural areas.[7] And if a health care facility is unable to access services, think of what is happening when elders search for care in a community based long-term care setting.

In addition to access problems, long-term care staff is inadequately trained to screen and detect mental health needs. Compounding this problem in the aged population is the fact that symptoms of mental illness in older adults are frequently displayed differently than in younger individuals. Health care professionals must be trained to recognize the oftentimes complex and sometimes subtle indicators of mental ailments which may present with physical symptoms. For example, mild confusion may be a sign of dehydration, depression, or dementia. A trained expert is needed to accurately detect the difference and to prescribe adequate treatment.

Furthermore, despite the existence of mental health screens designed and required in nursing home settings, studies indicate low rates of compliance related to the use of these tools. Fewer than half of nursing home residents with a serious mental illness receive proper preadmission screening. And, only 35% of those screened for mental health needs receive services.[8] This means that these statistics are likely higher due to inadequate

[5] National Ombudsman Reporting System Data - FY 2003
[6] "Policy Supporting Quality Mental Health Care In America's Nursing Homes," A Report developed by a subcommittee of the American Geriatric Society and the American Association of Geriatric Psychiatrists. (2003).
[7] ibid.
[8] ibid.

screening and lack of skills by staff to properly identify and address these important needs.

Impact on long-term care consumers

As a result, long-term care consumers suffer needlessly with conditions that are preventable and treatable. Untreated mental health needs can lead to more complex medical conditions and death. Failure to treat these needs impacts independence and quality of life and requires increased services and supervision.

For example, dementia's most predominant symptoms are behaviors that often pose a challenge to caregivers in terms of providing care. These symptoms may include verbal or physical behaviors such as screaming, biting, hitting, and scratching - any of which can result in injury to self or others. Confusion and disorientation, symptoms also often associated with dementia, increase the need for care assistance and supervision. Alternatively, an increase in behavioral symptoms can be an indication of other illness. Thus, caregivers must have adequate training to understand and manage verbal and physical behaviors, as well as to discern or detect symptoms which may indicate additional physical or mental illnesses requiring treatment.

Depression impacts a person's quality of life by taking away one's ability to experience hope and derive pleasure. Depression affects one's ability to maintain independence by participating in activities of daily living such as eating, bathing, and dressing and untreated depression may lead to weight loss due to malnutrition and dehydration. Depression may also impact an individual's memory which leads to further reliance on others for assistance in managing everyday tasks such as paying bills and taking medication. If left untreated, these conditions require more care and services from those in the workforce providing care.

Summary

In conclusion, NCCNHR supports the National Committee on Mental Health and Aging resolutions because residents in nursing homes and all who utilize long-term care services need a workforce that is responsive, knowledgeable, and skilled. The availability of such a workforce combined with a comprehensive person directed care process involving those who provide care can result in a long-term care experience that is both positive and fulfilling.

Testimony of Jacki McKinney, MSW
To the Policy Committee
Of the White House Conference on Aging
The Implications of the Increasing Diversity of Mid-Life and Older Americans for the Mental Health Workforce: A Consumer's Perspective
January 24, 2005

My name is Jacki McKinney and I am a family advocate specializing in mental health issues affecting African-American women and families. I am a founding member of the National People of Color Consumer/Survivor Network and a member of the board of trustees of the Bazelon Center for Mental Health Law. My motto in advocating for rights and choice is "nothing about us without us."

I wish to speak in particular about African Americans who are growing old in this country, whose issues are hidden among the many inequities of aging. The oldest among them were denied their civil rights and full participation in this society in their youth, due to racism and discrimination. Many did not pay into Social Security because they worked at menial jobs for the most minimal wages. Today, however, America's health strategy is that your life can only be as full as your purse. The best care is only available for the most money. Our seniors have the smallest checks/income and qualify for the lowest level of care and the least Social Security, if any at all.

The major issue for these seniors is assisted living. Yet current programs are designed for the wealthy or well-off. So poor people are relegated to nursing homes, even though they don't want or need that level of care. The nursing home becomes a prison for a person who is not sick but just needs some support. The alternative is a boarding home designed for people on SSI, who usually have long-term mental health issues, and that is not a supportive environment for enjoying a full life.

Medications have improved in recent years and society has become more enlightened around mental health issues. There is a large body of persons like me who, at age 40, 50, even 60 are recovering, released from institutions and entering the workforce and community for the first time. They need attention.

Let me tell you how I live.

I am 70 years old and the caregiver for my 90-year old mother, who suffers from Alzheimer's and is unable to care for herself. And for the past 10 years I have been caretaker of eight grandchildren.

Four of my 10 granddaughters continue to live with me. The oldest is 27 and has a 5-year-old and a 3-year-old. The next is 24, with a 3-year-old and a 1-year-old. The next is 18 and has a 2-year-old. The youngest is enrolled in her first year of college at the local state university. Six women and five children--we all live together in one house. I am the main source of support.

Their struggles and dreams to complete school and become self-sufficient are only as real as my ability to maintain the home and support them. This house of cards will crash if I do not support it. Yet we are not considered a family by most of the needs-based programs of support!

In my work I meet seniors, women who are struggling with the same issues, sandwiched between the needs of two generations. They are unable to buy a home, prepare for retirement or save money. Their parents, like my children, are struggling with issues of recovery and have histories of homelessness, mental health issues, institutionization, drug and alcohol addiction and all the accompanying problems. They have little or no work history. If I live another 10 or 15 years, I will have no one to depend on as a support system, because my children in their 50s and 60s will be dependent on their children at the same time I become in need of support.

I call this phenomenon the "double doomers."

I am suggesting that Americans need a single standard of care and living for all seniors. I have contributed everything I have to raise my grandchildren and keep my mother at home, removing the burden from the taxpayers. There are thousands like me. Wouldn't it be ironic if after years of struggle to recover, rejoin society, raise my grandchildren, removing the burden from the state and my community, I find myself living in the same conditions of poverty, isolation, poor living conditions that I fought so hard to recover from?

Thank you for your time.

Testimony of Margaret Gatz, Ph.D.
To the Policy Committee
Of the White House Conference on Aging
What We Have Learned and Where We Need to Go: Research in Mental Health and Aging
January 24, 2005

My name is Margaret Gatz. I am a representative of the American Psychological Association to the National Coalition on Mental Health and Aging. I am a Professor of Psychology at University of Southern California. Our psychology department is home to one of the nation's most long-standing doctoral training programs in clinical psychology and aging. I served as editor of Emerging Issues in Mental Health and Aging, the book that arose from this coalition's work and the Mini-Conference on Mental Health in support of the 1995 White House Conference on Aging.

I will highlight four issues that require research attention during the next decade.

1. We estimate that slightly over one fifth of older adults have mental disorders, including depression, anxiety disorders, substance use disorders, and dementia. However, there has not been a comprehensive nation-wide prevalence study of mental disorders in older adults in over two decades. The National Comorbidity Survey, which has guided understanding of prevalence and comorbidity of mental disorders at other ages, did not include those aged 55 and older. Research documenting the extent of mental health and substance use problems among older people is needed, including identification of problems newly arising in old age versus problems that are an extension of disorders earlier in life.

2. There is now a body of research that clearly demonstrates that mental disorders in older adults can be successfully treated with psychotherapy and with medications. That research has primarily focused on depressive disorders although also including anxiety disorders and substance use disorders; thus, more research is needed that encompasses the entire range of mental disorders experienced by older adults, that includes the oldest old, ethnically diverse older adults, and those with co-morbid physical conditions. We need more research about best ways to make evidence-based services and emerging best practices more accessible to older adults, such as co-locating mental health services in primary care facilities or "one-stop-shops" in the community; and we need more research about services integration, for example, the integration of mental health treatment with case management, physical exercise, alternative medicine, or peer support groups.

3. Existing research on risk factors for mental illness and on behavioral risk factors for physical illness suggests what prevention strategies should be effective to help older adults stay mentally healthy as well as physically, socially, and cognitively active and engaged. However, there is insufficient research identifying evidence-based prevention strategies and emerging best practices in the area of prevention, and there is insufficient research about how best to generate and sustain motivation for participation in prevention.

4. Given the increasing emphasis on consumer-directed care, for example, the "Cash and Counseling" approach for the delivery of in-home support services, mental health research might

usefully address the question of what capacities are required in order to be the director of consumer-directed care, how to assess capacity, and how to safeguard against quackery and scams for those who have mental illness or cognitive deficits. Toward this end, research on assessment of capacity and assessment of effective participation in decision-making is needed.

The decade ahead is a time of tremendous promise, given research advances that have already taken place, and a time of great challenge, given the growth of the older population. Research can provide the basis for best responding to that challenge.

Testimony of Sue Levkoff, ScD, SM, MSW
To the Policy Committee of the White House Conference on Aging
What We Have Learned and Where We Need to Go: Future Directions for Mental Health Programming
January 24, 2005

My name is Sue Levkoff. I represent the SAMHSA funded Positive Aging Resource Center, a member organization of the National Coalition on Mental Health and Aging. I am an Associate Professor in the Department of Psychiatry at Brigham and Women's Hospital and Harvard Medical School.

My remarks speak to What We Have Learned and Where We Need to Go: Future Directions for Mental Health Programming.

I will address three specific resolutions which the NCMHA has developed for submission to the 2005 White House Conference on Aging.

The first resolution I would like to address is that the White House Conference on Aging support the integration of older adult mental health and substance abuse services into primary health care and community based service systems. Recent research has supported the benefits of integrating medical and behavioral health service delivery for older adults, (Katon et al, 2002; Bartels et al, 2004). This has been accomplished through cross training, case management, consultation- liaison between mental health and primary care providers, or co-locating mental health and primary care providers in the primary care setting, (Katon et al, 1996; Unutzer et al, 2002; Bruce et al, 2004; Levkoff et al, 2004).

Some of the key components of primary care based mental health services include proactive patient screening and assessment, education and care management performed by a care manager to assess and educate the patient and to develop a care plan with the primary care provider, collaboration between primary care providers and mental health specialists in the supervision of the care manager, and clinician education and decision support for treatment, be it evidenced based algorithms for antidepressant medication management or psychotherapy.

Research has documented that collaborative care models that implement evidence-based changes at all levels of the primary care delivery system demonstrate the most impressive evidence in improving clinical outcomes for older adults with depression. This requires comprehensive changes in both internal organizational support (e.g., information technology, knowledge management strategies to support evidence-based practice) and external environmental support (e.g., community resources, public and private financial strategies, regulatory actions).

The second resolution I would like to address is that the White House Conference on Aging increase collaboration among aging, health, mental health and substance abuse consumer organizations, advocacy groups, professional associations, academic institutions, research entities, and all relevant governmental agencies to promote more

effective use of resources and to reduce fragmentation of services. Despite the breadth and availability of evidence-based practices for the treatment of mental health and substance abuse problems among older adults, a significant gap remains between the exiting knowledge base and its adoption into routine practice (Colenda et al., 2002). There is resistance to the implementation of evidence based practices by frontline service providers and program administrators as well as difficulties associated with their implementation.

The implementation of evidence-based practices across diverse service settings presents very specific challenges. Through our experiences in supporting EBP implementation through the SAMHSA Targeted Capacity Expansion Program, we found that service institutions differ greatly in their definition of what level of evidence is required to label a practice as evidence based, their readiness to adopt new evidence-based practices, and their capability to achieve financial and organizational sustainability of a new practice.

The existing MH/SA delivery systems, within their fragmented systems of care, do not work. The new system of care should focus on system integration, not cost reduction; coordination with primary care including training of primary care providers to recognize and treat mental health and substance abuse disorders, and coordination between primary and specialty care systems; treatment guidelines that are provider-friendly, and technical assistance for the adaptation of evidence based practices for specific sub-populations/ethnic minority groups. Current financing and reimbursement mechanisms must be revised to support the adoption of evidence based practices throughout the health care system.

State MH/SA and aging services organizations face formidable challenges in the implementation of EBPs. Years of separate funding streams for mental heath and substance abuse have created systems of care that are fragmented. This fragmentation is especially problematic for older adults with serious mental illness, who often deal with multiple and distinct care systems, including medical care, long-term care, mental health services, and aging network services.

Coordination and collaboration across state public health, behavioral health and medical systems and the larger network of aging services is crucial. Without this coordination, efforts to implement EBPs on a state-wide basis will remain fragmented. Consensus building and coordinated planning are necessary to reprioritize program agendas and reallocate resources crucial for successful implementation of evidence based practices into state-funded MH/SA service settings.

The third resolution I wish to address is that the 2005 White House Conference on Aging ensure that mental health and substance abuse services for older adults are age appropriate, culturally competent, and consumer-driven. The information is available; front line service providers need to be able to readily access, retrieve, and synthesize existing evidence in support of evidence based practices for treating mental health and substance abuse problems in older adults. These frontline services providers also need to have access to experts who can help them ensure that the evidence based practices they

choose to implement are culturally competent for the intended population. The needs of older adults from ethnic minority groups must be addressed, as such populations face special challenges in receiving culturally appropriate MH/SA services.

It is of vital importance that MH/SA services be consumer-driven. This means providing older adults with a meaningful choice of services, offered in different settings, and they be given the opportunity to participate in the care processes. Consumer-driven MH/SA services also require health education and prevention to reduce the prevailing stigma surrounding mental health problems; such services are also crucial for promoting positive aging. Existing consumer organizations such as OACHMA and the Mental Health Clearinghouse in Pennsylvania can provide needed input to ensure that services are consumer-driven.

I thank you for your consideration of these remarks. If I can provide any additional information, please do not hesitate to contact me at sue_levkoff@hms.harvard.edu.

Testimony of Tess Scannell
to the Policy Committee
Of the White House Conference on Aging
Community Service and Older Adults mental Health and Well Being
January 24, 2005

Good Morning, and Thank you, Madam Chairman, and Mr. Blancato, and Ms. Hunt, members of the Policy Committee, for your time. I'd also like to thank our host, the National Coalition on Mental Health and Aging, for allowing us this opportunity to discuss service and volunteering as beneficial to the mental health of older adults.

As you well know, we are learning more about the mind/body connection -- there is an abundance of research that supports what those of us in the volunteer world already know – there is healing power in helping others. Numerous studies now document the value of volunteering for all segments of the population (and I have cited some of it in the written version of my testimony). But, older adults, in particular, reap tremendous physical and mental health benefits in their own lives by reaching out and giving to others. And the mental health benefits gained through helping others are as important as the physical.

Older adults who volunteer remain part of the social fabric and stay connected to others which helps them feel part of a greater community. This feeling – this connection -- is an important factor in fighting depression and promoting healthy aging. Studies show that volunteers release brain endorphins that lower blood pressure and relieve pain and stress, much the same way as a good physical workout.

Spending time tutoring and mentoring a child, delivering meals to the homebound, or helping out in the community through some other activity, keeps older adults involved and helps them to maintain their intellectual abilities. So, there is an unmistakable connection between volunteering and enhanced mental health.

And, beyond the mental health benefits to the individual volunteer, are the contributions that older Americans make to their communities through their volunteerism. Seniors who volunteer are the most active volunteers within the community. According to a recent survey by the Independent Sector, almost 44 percent of all people age 55 and over volunteer at least once a year and more than 35% reported that they had volunteered within the past month. These volunteers (approximately 26.4 million of them) give an average of 4.4 hours per week to the causes they support in their communities. This is a total of approximately 5.6 billion hours of their time – a current value of $77.2 billion to nonprofit organizations and other causes in this country.

Many of these volunteer hours by older persons have been used to enhance care and help build closer ties between the community and the mental health system. Throughout the country, Departments of Mental Health rely on older volunteers to provide extra "hands" and emotional support to clients and their families. These

volunteers enhance their own mental health while they are helping to dispel the stigma and misconceptions abound mental illness.

It is widely acknowledged that volunteering contributes to one's sense of self-worth and well-being. But lesser known, is the duality of volunteering. That is, that volunteering benefits those who are served by it – clients, communities, and society as a whole – while it, at the same time, contributes to the emotional health of those engaged in it. And, volunteering is an effective way to support and extend the delivery of human services.

So, where do we go from here with all of this information? When you consider that about 76 million baby boomers will be Winding down their careers with combinations of work, volunteering and leisure activities, it seems self-evident that increased emphasis should be placed on collaborations among aging, health, advocacy groups, professional organizations and government agencies and others to promote volunteerism as part of the process toward healthy aging and healthy communities. I believe this country's new mantra should be, "Exercise, Eat Right, and Get Involved."

Again, Thank you, again, Madame Chairman, Mr. Blancato, and Ms. Hunt for your time.

Relevant Research

1. The Effects of Volunteering on the Physical and Mental Health of Older People, Terry Y. Lum and Elizabeth Lightfoot, University of Minnesota, 2005 Sage Publications.

2. Senior Sense: Getting Back by Giving Back: Healthy Aging through Volunteering, Mary McCallum, Council on Aging of Southeastern Vermont, March, 2002.

3. The Healing Power of Service, Edward V. Brown, MD, Oregon, USA, SelfGrowth.com/health-healing, 2002.

Testimony of Sanford I Finkel, MD
To the Policy Committee
Of the White House Conference on Aging
We Have Learned and Where We Need to Go: 2005 and Beyond
January 24, 2005

My name is Sanford I. Finkel, MD. I serve as Chair of the National Coalition of Mental Health and Aging (NCMHA). Additionally, I am Senior Vice President of Medical Affairs at Council for Jewish Elderly in Chicago, Illinois and Clinical Professor of Psychiatry at the University of Chicago Medical School.

The recommendations that emanate from the White House Conferences on Aging (WHCoA) have resulted in legislation and/or policies that have profoundly and positively affected older people in this country, including those with mental health needs.

The 1951 White House Conference on Aging was an impetus for the founding major consumer organizations, including the National Council on Aging, and the 1961 White House Conference on Aging pointed directly to the ensuing Medicare and Medicaid legislation, ensuring support for health services for older Americans.

The 1971 White House Conference on Aging underlined the importance of research and, within a handful of years, the National Institute on Aging (NIA), with its emphasis on cognitive impairment, and the National Institute of Mental Health Center for the Research on Mental Health and the Aging were established.

Continued progress in mental health and aging resulted from a 1981 Conference on Aging. Over the ensuing decade the $250 cap on outpatient mental health services under Medicare Part B was eliminated, and clinical psychologists and clinical social workers were reimbursed for care provision. Groundwork was laid for OBRA 87 with its upgrading of mental health services in long-term care facilities. Further, the White House Conference led directly to the establishment of a high-level Federal policy to investigate and enhance research in the area of Alzheimer's disease. In addition, increased focus on public information and prevention led to major initiatives on the part of NIA, NCOA, NIMH, and AARP.

In February 1995, the NCMHA conducted a White House Mini-Conference on Emerging Issues in Mental Health and Aging. The priorities developed at this mini-conference, which are outlined in the Margaret Gatz-edited, *Emerging Issues in Mental Health and Aging,* were brought to the White House Conference on Aging later that year, where three of the top ten resolutions adopted were on mental health. As a result, the 1995 WHCoA has led to greater attention on intergenerational issues and caregiving, as well as calling attention to the integration of mental health and physical health within primary care and other settings. Further, recommendations in the research arena encourage policies towards the 1990s being the "decade of the brain" with considerable research attention and emphasis on Alzheimer's disease and other dementing illnesses.

We now need to turn our attention toward the guaranteed increase in the number of people age 65 and older experiencing disability due to mental disorders, substance use, or cognitive impairment, particularly given the fact that the number of people in the United States over the age of 65 soon will grow from one in eight to one in five. This amplification paired with a longer lifespan, more time spent living in the community, and additional years in the workplace will result in a significantly decreased quality of life and level of functioning for a percentage of the population that is impossible to neglect. We hope that our resolutions aimed at supporting and assisting Americans with these disabilities will be considered.

While we certainly commend Dorcas Hardy and the Policy Committee's exploration of mechanisms to have the 2005 WHCoA put an even greater emphasis on implementation of recommendations, it remains the case that there are those who minimize the importance and impact of White House Conferences on Aging. However, the record clearly shows that many recommendations become law or policy, positively impacting our older Americans for generations to come.

Thank you.