



# **Community Integration for Older Adults with Mental Illnesses: Overcoming Barriers and Seizing Opportunities**

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# **Contents**

<b>Executive Summary .....</b>	v
<b>Introduction .....</b>	1
<b>Section I: A Vulnerable Population .....</b>	3
<b>Section II: Barriers to Community Integration .....</b>	11
<b>Section III: Prevention .....</b>	21
<b>Section IV: Successful Practices.....</b>	27
<b>Conclusion</b>	39
<b>References .</b>	41
<b>List of Contributors .....</b>	49

# Executive Summary

*Olmstead v. L.C.*, the 1999 U.S. Supreme Court decision which held that unnecessary segregation of individuals in institutions is discriminatory, challenges States and communities to find appropriate alternatives for older adults with serious mental illnesses. Older adults are doubly stigmatized by their mental disorder and by their age, and they fall victim to a general lack of long-term care opportunities for older Americans.

This report, *Community Integration for Older Adults with Mental Illnesses: Overcoming Barriers and Seizing Opportunities*, is the third in a series of reports prepared by the National and Statewide Coalitions to Promote Community-Based Care under Olmstead project, sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services. It is designed to help State and local Olmstead coalitions understand the barriers that older adults face and learn about the innovative solutions being adopted and adapted across the country.

## A Vulnerable Population

The number of older adults in this country is increasing rapidly, and so, too, are their needs for long-term mental health services and supports. Seven million people age 65 and older in the United States (20 percent of the older adult population) have a psychiatric illness, and that number is expected to double to 15 million in the next three decades. Older adults with serious mental illnesses receive lower quality of care and have higher mortality rates than older adults without a mental disorder. They are also three times more likely to be placed in nursing homes.

Frequently, older adults with mental disorders have comorbid medical conditions that complicate their treatment and long-term stability; they also may have alcohol-related or drug use problems. One in six older adults lives in poverty, and they are increasingly likely to be members of minority groups. Suicide rates are highest among Americans age 65 and older.

Most older adults with mental disorders live at home. However, among older adults with serious mental illnesses in institutions, 89 percent reside in nursing homes. Many older adults who left State psychiatric hospitals under deinstitutionalization were actually “transinstitutionalized” into nursing homes. Community services for people with serious mental illnesses failed to materialize, and financial incentives, rather than individual needs or desires, drove placement decisions.

The Preadmission Screening and Resident Review (PASRR) provisions of the Nursing Home Reform Act of 1987 have led some States to identify people with serious mental illnesses who can be more appropriately treated in the community and plan services for them. Other States comply minimally with the PASRR requirements.

## Barriers to Community Integration

Numerous fiscal, service system, clinical, and societal barriers make it difficult for older adults with serious mental illnesses to find long-term, community-based treatment, housing, and supports. Current reimbursement and fiscal policies tend to favor inpatient versus outpatient care; medical versus psychological care; acute versus chronic care; and more restrictive versus less restrictive care. In particular, Medicaid funding is largely focused on institutional services, and Medicare coverage for mental health services is limited.

Older adults with serious mental illnesses may be particularly ill-served in managed care programs. Many managed care plans lack the full array of community support and residential rehabilitation options that older adults with serious mental illnesses require, and such plans may have fiscal incentives to avoid individuals who have comprehensive, long-term treatment needs.

A significant number of older adults with serious mental illnesses and substance use disorders

remain unrecognized and untreated. Service system fragmentation and lack of training for both mental health and primary care practitioners are partially to blame. Many older adults prefer to receive their mental health care from their primary care providers, but most primary care practitioners lack training in geriatrics or mental health, and far too few mental health specialists lack training in geriatrics as well.

Though older adults represent 13 percent of the U.S. population, they receive only 6 percent of community mental health services. Even when services are available, older adults face transportation, language, and cultural barriers. In addition, housing options are particularly limited for older adults. For lack of alternatives, many older adults with serious mental illnesses live in facilities that are not specifically designed for people with mental disorders, such as assisted living facilities, or in facilities that may be poorly regulated and offer few services, such as board and care homes.

The stigma of mental illnesses and substance use disorders, and the lack of understanding that these problems can be successfully treated in older adults, keep many older Americans from seeking the help they need. Insufficient attention to prevention of mental disorders and excess disability associated with mental disorders also limits the type and scope of services that older adults receive.

## **Prevention**

The Surgeon General's 1999 report on mental health defines prevention broadly as the development of interventions for "reducing the risk of developing, exacerbating, or experiencing the consequences of a mental disorder" (p. 341). Preventive interventions focus on decreasing risk factors—such as isolation, poverty, and bereavement—that place older adults at risk for developing mental disorders or suffering a relapse of a current condition—and increasing protective factors that guard against negative outcomes. Protective factors for older adults include family support; formal support groups; health and social services; and opportunities for new, productive social roles.

Both support groups and peer counseling have been shown to be effective for older adults at risk for depression. Bereavement support groups, in particular, can help improve mental health status for widows and widowers. Older adult consumer counselors can talk to their peers from firsthand experience about the symptoms of mental illnesses and substance abuse disorders and the fact that treatment works.

Because caregiver distress is a significant risk factor for institutionalization, those interventions that support caregivers and give them needed respite have been shown to be effective in delaying or preventing nursing home placement for older adults with mental disorders. In general, interventions for caregivers that are individual and intensive have proven more effective than less potent and focused interventions.

## **Successful Practices**

Progress in the treatment of mental disorders and in the care of older adults means that older adults with serious mental illnesses no longer must be consigned to live out their lives in institutional care. Increasingly, long-term care for older adults with serious mental illnesses is conceived of as a range of services needed to maintain an individual in the least restrictive setting possible.

Meaningful services for older adults with serious mental illnesses are based on the following underlying principles: services should be accessible, culturally sensitive, comprehensive, flexible, coordinated, multidisciplinary, and continuous. Successful programs feature accurate assessment, outreach, interdisciplinary treatment, education, collaboration with other agencies, and home care services.

States and communities have implemented a number of evidence-based and promising practices for older adults with serious mental illnesses. These include the following:

*Screening and Assessment.* Routine screening by health care providers for cognitive, behavioral,

and emotional disorders is recommended to ensure access to quality mental health care. Evidence for the effectiveness of standardized screening is provided by evaluation of an integrated toolkit that is now a standard part of care in the public mental health system in New Hampshire. This toolkit also is being piloted in other States.

***Home and Community-Based Mental Health Outreach Services.*** Older adults receiving outreach services have shown increased likelihood of receiving case management services, decreased mental health symptoms, and decreased incidence and length of psychiatric hospitalization. Services modeled after the Gatekeepers program, which uses community members as frontline assessors, have been successfully implemented in both urban and rural areas.

***Mental Health Treatment.*** Older adults with serious mental illnesses can benefit from both pharmacological and psychosocial approaches. Community-based, multidisciplinary mental health treatment teams are effective with older adults. Psychiatric home care can benefit older adults who have functional impairments that limit their ability to live independently.

***Integrated Models of Service Delivery in Primary Care.*** Evidence supports incorporating behavioral health care into medical settings. Medication, psychotherapy, and psychiatric consultation can reduce medical costs, with the greatest savings among older adults.

In addition, several promising approaches provide direction for future development of community-based services. These include supported housing, attention to cultural competence in service delivery settings, and a focus on consumer involvement and empowerment. The Older Adult Consumer Mental Health Alliance has become an effective advocate for older Americans with serious mental illnesses and is

promoting a message of hope and recovery through support for legislation, education, fundraising, and a national membership drive.

Finally, because no one service system is equipped to meet the multiple and complex needs of older adults with serious mental illnesses, effective services require coordination and collaboration among providers of aging, mental health, health care, substance abuse, and social services. Community coalitions have been instrumental in bringing disparate resource together to provide coordinated services. These coalitions exist at the local, State, and national level.

## ***Conclusion***

The vision of the Substance Abuse and Mental Health Services Administration, which oversees Olmstead planning for people with serious mental illnesses, is “a life in the community for everyone.” This goal closely mirrors the vision articulated in the Final Report of the President’s New Freedom Commission on Mental Health, which emphasizes that all people with mental illnesses should have access to effective treatment and supports to enable them to live, work, learn, and participate fully in their communities.

Though progress has been made in the care of older adults with serious mental illnesses, much remains to be done to achieve the fundamental systems transformation envisioned by the New Freedom Commission and to support full community integration. In the past, communities may have wanted to further integrate older adults with mental illnesses into community life. Today, the *Olmstead* decision and the New Freedom Commission provide specific guidance for accomplishing this goal.

# Introduction

In 1999, the U.S. Supreme Court declared in *Olmstead v. L.C.* that unnecessary segregation of people with disabilities in institutions is a form of discrimination that violates the 1990 Americans with Disabilities Act (ADA). This decision has a significant impact on older adults who have serious mental illnesses. Frequently consigned to nursing homes due to lack of community-based care, many older adults with mental illnesses could live successfully in their communities, and even in their own homes, with appropriate services and supports.

The lack of appropriate long-term care affects all older Americans. Those with serious mental illnesses are particularly vulnerable. They face the double burden of being elderly in a youth-oriented culture, and of having a disease that is still poorly understood and accepted. Yet older adults with serious mental illnesses are *people first*. They are mothers and fathers, grandparents and great-grandparents, and sisters and brothers.

Community-based services for older adults come in many forms: A nurse may visit every week or so to check an older adult's health and medications; senior center staff may connect the person with a counselor; the letter carrier may call a community team when she suspects a crisis; a peer may visit to share experience, hope, and advice. These services and supports keep people in the community, and help those who have recently been in a hospital or nursing home make a successful transition back to the community.

Unfortunately, in many communities, fragmented service systems leave the individual, or more likely a caregiver or advocate, to negotiate among providers of mental health, elder care, and home health care services. Frequently, individuals fall through the cracks and their caregivers don't know where to turn.

To help communities plan for services for people of all ages, the Substance Abuse and Mental Health Services Administration (SAMHSA) of the U.S. Department of Health and Human Services has created the National and Statewide Coalitions to Promote Community-Based Care under Olmstead project for people with serious mental illnesses. This report, *Community Integration for Older Adults with Mental Illnesses: Overcoming Barriers and Seizing Opportunities*, is the third in a series produced by the Olmstead project. The first addressed adults with mental illnesses and the second dealt with children with emotional and behavioral disorders.

Specifically, this paper describes the characteristics and service needs of older adults with serious mental illnesses, barriers to community integration, prevention interventions, and successful program and system practices. It also profiles several successful programs. Ultimately, the paper answers the basic question: How can we best keep older adults with mental illnesses in the community?

# SECTION I

## A Vulnerable Population

America is aging. By 2030, adults age 65 and older will account for 20 percent of the population, up from 13 percent in 2000. People 85 years and older comprise the most rapidly growing segment of the U.S. population (U.S. Administration on Aging, 2001).

An aging population brings with it a host of medical and social concerns, not the least of which is the care of older adults with serious mental illnesses. Some older adults have had serious mental illnesses most of their adult lives; others have had periodic episodes of mental illness throughout their lives; others develop a serious mental illness in late life, often exacerbated by bereavement and loss, poverty, and lack of social support.

The major focus of this report is on those adults who have had recurring or periodic episodes of serious mental illnesses. These illnesses, including schizophrenia, major depression, bipolar disorder, and schizoaffective disorders, may result in functional impairment that substantially interferes with or limits one or more major life activities. (For a complete description of the term “serious mental illness,” see the *Federal Register*, May 20, 1993.) Many of these individuals are at risk for institutionalization, or currently reside in nursing homes or psychiatric hospitals, though their illnesses do not warrant custodial care.

Alzheimer’s disease and other forms of dementia meet the criteria for “functional impairment” and may complicate treatment for a concurrent serious mental illness. However, it is beyond the scope of this report to discuss the full range of service needs and innovative programs for Alzheimer’s patients and their families. Many State Agencies on Aging and Area Agencies on Aging have information and advocacy efforts on behalf of people with Alzheimer’s disease and their families.

To classify older adults, one taxonomy divides aging adults into young-old (age 65-75), old (age 75-85), and old-old (age 85 plus) (U.S. Administration

on Aging, 2001). Most of the old and old-old individuals in this country are women. Older women are more likely to be institutionalized, to suffer disproportionately from chronic disabilities and disorders, to be widowed, to live alone, and to be poor (U.S. Administration on Aging, 2001; Estes, 1995). In this report, older adults refer to men and women age 65 and older, unless otherwise stated.

### **Demographic and Mental Health Profile of Older Adults**

The picture that emerges of older adults in this country is one of individuals who—by virtue of medical illness, poverty, minority status, and isolation—are susceptible to worsening psychiatric symptoms and institutionalization and to the development of serious mental illnesses in later life. However, with appropriate services and supports, as discussed elsewhere in this report, most older adults with serious mental illnesses can live successfully in the community.

#### **Mental Health Problems**

Mental disorders are not a normal part of aging, yet a significant number of older adults have these serious but treatable diseases. Currently, 35 million people age 65 and older reside in the United States, of which 7 million (20 percent) have a psychiatric illness (Jeste et al., 1999; U.S. Census Bureau, 2000). This number is expected to double to 15 million over the coming three decades (Jeste et al., 1999).

Projections of a rapid growth in the number of older adults with psychiatric disorders over the coming decades are largely due to the maturation of the “baby boomer” cohort, which has 76 million members. The first group of this cohort will reach age 65 in 2011. Greater longevity associated with improved health care and other social factors also will add to the anticipated population of older adults with mental disorders.

Estimates of the number of adults age 55 and older with serious and persistent mental illnesses range from 0.8 percent (Kessler et al., 1996) to 2 percent (Colenda et al., 2002). Older adults with serious mental illnesses receive lower quality of care and have higher mortality rates than older adults without a mental disorder (Druss et al., 2001). They are also at significant risk of being institutionalized.

Older adults with serious mental illnesses are three times more likely to be admitted to a nursing home than older individuals without serious mental illnesses (Bartels et al., 2000). Though most older adults with serious mental illnesses live in the community, 89 percent of those individuals with serious mental illnesses who are institutionalized live in nursing homes (U.S. Department of Health and Human Services, 1999).

For many individuals with serious mental illness, nursing home placement reflects a lack of community-based alternatives. In addition, a combination of behavioral, medical, and social needs presents significant challenges. Individuals placed in nursing homes generally have more severe overall and negative psychotic symptom ratings, worse general health, less social support, and more aggressive and problem behaviors (Bartels et al., 1997; Meeks et al., 1990). In particular, severe deficits in activities of daily living, as well as a lack of available family members, have been identified as the most uniquely predictive of nursing home residence (Bartels et al., 1997).

Yet aging with a serious mental illness does not necessarily mean a decline in functioning. Indeed, research on people with schizophrenia contradicts the notion of serious mental illness as a lifelong, debilitating condition (Harding et al., 1987). Notes Cohen (2000), "Increasingly, aging for persons with schizophrenia, like aging for persons in general, is no longer viewed as a decremental process but one of adaptation, compensation, and plasticity" (p. 300).

## Risk of Suicide

Suicide rates increase with age and are highest among Americans age 65 and older. While this

group accounts for only about 13 percent of the U.S. population, Americans age 65 and older account for 20 percent of all suicide deaths (*The Surgeon General's Call to Action to Prevent Suicide*, 1999).

Depression is a significant risk factor for suicide in older adults and may be linked to bereavement and loss (U.S. Department of Health and Human Services, 1999). Depression also may co-occur with other serious mental illnesses. For example, more than two-fifths of older adults with schizophrenia show signs of clinical depression (Cohen, 2000). Prevention of suicide is a serious concern for older adults, who are more likely to be successful in their suicide attempts than any other age group (Smyer, 1995).

## Comorbid Medical Conditions

Most older adults have one chronic medical condition, and many have multiple disorders, such as arthritis, hypertension, heart disease, cataracts, or diabetes (U.S. Administration on Aging, 2001). It is not surprising, therefore, that comorbid medical conditions are common in older adults with serious mental illnesses. In fact, the hallmark of late-life depression is its coexistence with medical illness and its association with poorer outcomes (Weintraub et al., 2002).

Medical illnesses may arise independently of mental illnesses, but may also be associated with them. For example, a new epidemiological study finds that chronic depression (lasting an average of about 4 years) raises the risk of cancer by 88 percent in older people (U.S. Department of Health and Human Services, 1999). Conversely, poor physical health is a key risk factor for mental disorders (U.S. Administration on Aging, 2001).

Coexisting medical conditions complicate an individual's assessment and treatment. Because most older adults are treated in primary care settings, the medical illness may overshadow the mental illness and result in inadequate recognition and treatment for the mental disorder. Researchers estimate that nearly half of comorbid medical conditions in people with schizophrenia are missed (Cohen, 2000). Also, a mental disorder may make it more difficult for

an individual to care for his or her physical health needs. Left untreated, mental disorders can turn a minor medical problem into a life-threatening condition (U.S. Department of Health and Human Services, 1999). Medical comorbidity is present in the majority of older adults with a serious mental illness (Gierz & Jeste, 1993) and is associated with worse medical outcomes and higher mortality compared to individuals without mental illness (Druss et al., 2001). In general, older adults with serious mental illnesses are at risk for receiving lower quality of health care, inappropriate prescriptions, and reduced access to needed services (Bartels, 2002).

## **Substance Abuse Problems**

Older adults are at increased risk for alcohol-related problems and accidental or intentional misuse of prescription drugs. Up to 15 percent of community-residing older adults report problem drinking (Oslin, 2000), and misuse of prescription medications is common (Gallo & Legowitz, 1999). Researchers have found that older adults are more susceptible to the effects of alcohol on the brain and that physiological changes in the body keep alcohol in an older adult's system longer (CSAT, 1998).

Likewise, age brings with it changes in the absorption, distribution, metabolism, and excretion of psychotropic drugs (U.S. Department of Health and Human Services, 1999). These factors may result in altered blood levels of medications, prolonged effects, and increased risks for side effects, especially for individuals who take multiple medications.

Interactions among prescription drugs and between medications and alcohol are also a risk factor for older adults. Individuals over the age of 65 take more prescription and over-the-counter medications than any other age group in the United States, and any use of drugs in combination with alcohol carries risk. The abuse of these substances raises that risk (CSAT, 1998).

Like their younger counterparts, older adults with mental disorders may be especially prone to the adverse effects of drugs or alcohol. Most commonly,

"dual diagnosis" of substance abuse and mental illness in older persons consists of alcohol misuse and depression or anxiety disorders. However, it is likely that the next generation of retired older persons will have increasing rates of co-occurring illicit drug abuse. Finally, older adults with severe mental illnesses are especially vulnerable to the effects of alcohol or drugs of abuse, so that even small amounts of psychoactive substances may have adverse consequences for individuals with schizophrenia and other brain disorders (Bartels & Liberto, 1995; Drake et al., 1989). Individuals with co-occurring mental and substance use disorders are at heightened risk for a number of adverse outcomes, including institutionalization, homelessness, and death.

## **Poverty**

One in six older adults was living below the poverty level or was near-poor in 1998 (U.S. Administration on Aging, 2001). Among older people, those at greater risk for poverty include women, African Americans, people living alone, very old people, those living in rural areas, or those with a combination of these characteristics. Poverty is a known risk factor associated with mental illness (U.S. Administration on Aging, 2001). In addition, most people with serious mental illnesses are poor by virtue of their inability to work consistently, if at all, and their reliance on public benefits.

## **Minority Status**

Minority groups are expected to represent 25 percent of the older adult population in 2030, up from 16 percent in 1998 (U.S. Administration on Aging, 2001). Members of minority groups are more likely to be poor, to have greater health problems, and to receive inadequate health and mental health care (Estes, 1995; U.S. Department of Health and Human Services, 1999). Both older adults and minority group members are more likely to seek care from primary health care providers, where their mental health and substance abuse problems often go undetected and untreated.

## Caregivers

Contrary to the view that an increasingly mobile society relegates older adults to impersonal or institutional care, the majority of older Americans live in the community in a family setting (U.S. Administration on Aging, 2001). Some 13 million individuals in this country provide unpaid care to their older relatives (U.S. Department of Health and Human Services, 1999). The average age of caregivers is 60, three-quarters are women, and one-third are employed (U.S. Administration on Aging, 2001).

Given appropriate support, family caregivers can delay or prevent institutionalization of their ill relatives, a fact that will be discussed in more detail in the prevention section of this report. However, family caregivers themselves are at risk for mental disorders. One source of data reveals that 46 percent of caregivers are clinically depressed, but only 10 percent to 20 percent use formal services (U.S. Administration on Aging, 2001). Also, lack of caregivers is a significant problem for people with no children or spouse and for the very old (85 plus). Thirty percent of older adults in the community live alone (U.S. Department of Health and Human Services, 1999).

## ***The Changing Locus of Care***

For most of the 20<sup>th</sup> century, States cared for older adults with mental illnesses and dementia in State hospitals or asylums. However, the role of these institutions has diminished significantly since the mid-1950s, when more than a half million individuals were State hospital inpatients. By 1998, that number had dropped to 57,000, despite a huge increase in the general population (Lamb, 1998).

Much of this decrease in the State hospital census can be attributed to deinstitutionalization, an outgrowth of three significant changes in American society. First, in the mid-1950s the introduction of antipsychotic medications gave rise to hopes that, with their symptoms under control, people with serious mental illnesses would be able to live successfully in the community. Second, creation of

the Medicaid and Supplemental Security Income (SSI) programs in the mid-1960s provided financial incentives for community care. Finally, consumer, family, and advocacy groups sought to address well-publicized abuses in State hospitals by seeking treatment in the least restrictive setting for people with serious mental illnesses. As a result of these changes, large numbers of people with serious mental illnesses made the transition to the community.

The initial phases of deinstitutionalization focused on younger adults. For example, in 1984, older adults still accounted for 22 percent of State psychiatric hospital residents (Semke et al., 1996). However, over the last several decades, State psychiatric care of older adults has declined.

Between 1972 and 1987, the number of hospitalized older adults with mental illnesses declined by 82 percent (American Psychiatric Association, 1993), followed by a subsequent decline of 33 percent between 1986 and 1990 (Atay et al., 1995). The rate of decline was greater for older adults than for adults ages 18 to 64 (Semke et al., 1996). As a result, State hospital patients today are predominantly younger adults who have shorter stays and increased discharge rates (Semke et al., 1996).

When deinstitutionalization began, advocates hoped to move almost all hospital patients to the community. Many assumed that funding for an individual's care would follow her or him into the community. However, this rarely occurred.

Dollars were tied to services, not to individuals, so there was no guarantee that a person would receive the treatment and supports required for successful adjustment and maintenance in the community. States had many pressing health, social service, and other nonrelated needs, and much of the money that became available with the closing and downsizing of State hospitals was redirected to those areas.

In 1963 Congress passed the Community Mental Health Centers Act, in large part to address this problem. The legislation provided Federal funding for a nationwide network of community mental health centers (CMHCs) to provide community-

based services for people with mental illnesses, prevent unnecessary institutionalization, and provide continuing care in the community for those who had been discharged from State mental health facilities and who could not afford services in the private sector.

In the ensuing decades, CMHCs have become a key community resource for many people with serious mental illnesses. But the vast array of services and supports envisioned by the CMHC legislation never materialized. Fewer CMHCs than anticipated were created, and they offered primarily clinic-based services that were inaccessible or inappropriate for individuals with the most serious disorders. Older adults, in particular, are inadequately served by most CMHCs, a fact that will be highlighted in the next section of this report.

## **The Transinstitutionalization Trend: The Role of Nursing Homes**

The experience of many older adults who moved out of State hospitals can best be described as “transinstitutionalization” rather than deinstitutionalization. Despite a public mandate that resources and services be shifted from State hospitals to community settings, shortfalls in services and unintended fiscal incentives under Medicaid resulted in growing numbers of patients with serious mental illnesses, particularly older people, being moved into nursing homes.

Hunter (1999) notes, “Economics drove much of the transinstitutionalization of the elderly as states attempted to shift costs to the federal government, using Medicaid and Medicare benefits, by placing elderly people in nursing homes and other residential centers of various types” (p. 27). While some States considered individual need for nursing home services in making placements, others gave little thought to the appropriateness of the placement, and even less to personal preference.

Almost all older adults with serious mental illnesses receiving care in institution-based settings reside in nursing homes. Among older adults with serious mental illnesses in institutions, 89 percent

reside in nursing homes, 8 percent in State or county hospitals, and 3 percent in Veterans Administration or other general hospital settings (Burns, 1991).

Prevalence studies underscore recognition that nursing homes have become the new mental institutions for older adults affected by mental health problems. Among the 1.6 million older adults currently residing in nursing homes (Jones, 2002), nearly two-thirds have a mental illness or psychiatric symptoms (Smyer et al., 1994). The most common psychiatric conditions in nursing homes are dementia complicated by behavioral symptoms, mood disorders, anxiety disorders, and serious mental illnesses such as schizophrenia and other psychotic disorders.

## **Factors Associated with Nursing Home Placement**

Nursing home care may have particular benefits for older adults with mental disorders who have intensive functional and medical care needs. In general, nursing homes may be able to provide more technically advanced services designed to meet individual needs in an immediate and timely fashion.

Current regulations and oversight of prescribing in nursing homes have substantially decreased inappropriate use of antipsychotic agents (Kidder & Kalachnik, 1999; Office of Inspector General, 2001a). In recent years, many nursing homes have responded to increased Federal and State monitoring and regulation, and have initiated contracts with specialty mental health providers. However, a shortage of mental health expertise onsite or provided by outside professionals remains a serious problem at a great number of nursing homes (Reichman et al., 1998).

Despite the regulatory intent of Preadmission Screening and Resident Review (PASRR), inappropriate placement of individuals with mental illnesses in nursing homes remains an unfortunate reality. For example, a study of the living preferences of older adults with mental illnesses residing in nursing homes found that approximately 40 percent of nursing home residents with serious mental illnesses

believed that a community-based residence would more appropriately meet their care needs and living preferences. Similarly, nursing staff determined that approximately 50 percent of these older nursing home residents with severe mental illnesses in this study group were clinically appropriate for living in supported residential settings in the community. Of significance for State Olmstead plans, residents and clinicians differed in their opinion of which residents were most appropriate for living in the community and also differed on their opinion of the most appropriate alternative living setting. Consumers overwhelmingly indicated that the most appropriate alternative living setting would be in their own home or apartment, whereas clinicians indicated that supported group homes or congregate assisted living settings were most appropriate (Bartels et al., 2003).

Several factors contribute to inappropriate institutional placement of older adults with psychiatric disabilities. First, service providers or settings to support older adults with mental illnesses in integrated, community situations are lacking. Second, while intermediate levels of care would be appropriate for many institutionalized older adults, Medicaid and other funding sources for these settings are highly variable and limited. Third, lack of family support, or lack of education and support for family caregivers, places individuals with serious mental illnesses at risk for nursing home placement if their symptoms worsen, their behaviors change, or they experience complications of comorbid medical illnesses.

### ***The Preadmission Screening and Resident Review (PASRR)***

To prevent inappropriate placement of people with mental disabilities in nursing homes, Congress enacted preadmission screening and resident review (PASRR) requirements, pursuant to Title 19 of the Omnibus Budget Reconciliation Act of 1987, also known as the Nursing Home Reform Act. PASRR requires States to develop and implement a preadmission screening process for individuals with mental illnesses who are applying for admission to Medicaid-certified nursing facilities.

Based on an independent assessment, States must determine if applicants are appropriate for placement in a nursing facility and whether they need active treatment for their mental health conditions. Those applicants who do not meet the full criteria for skilled nursing care and whose primary needs consist of psychiatric care are to be referred to appropriate, alternative settings.

The effectiveness of PASRR has been hotly debated. Critics say it results in few denials of admission to or discharges from nursing homes and that the money could be better spent on residential services. Supporters believe it can identify nursing home residents with serious mental illnesses, determine their needs, and establish responsibility for services.

The PASRR program was established for a variety of reasons. First, there was concern that States had systematically moved younger individuals from State mental health facilities into nursing homes to pass along the cost of care to the Federal government. In general, this has been found not to be true. A 1996 review of nursing home data by the Indiana State Department of Health found that 89 percent of residents were age 65 or over and 70 percent were age 85 and over. An Office of Inspector General (OIG) study (OIG, 2001b) was unable to determine the actual number of residents under the age of 65 with mental illnesses. Data reviewed by the OIG ranged between 1.6 percent and 20 percent.

A second concern was the poor conditions in some nursing homes. Advocates hoped that PASRR would provide additional pressure on States to develop alternative placement options to better meet the needs of older adults with mental illnesses inappropriately placed and inadequately served in nursing homes.

The reality is that PASRR only applies to a minority of nursing home applicants and residents, i.e., those individuals with serious mental illnesses. The PASRR process also excludes individuals who have a primary diagnosis of dementia, including Alzheimer's disease. Residents with a nonprimary dementia diagnosis are also excluded if they do not

have a primary diagnosis of a serious mental illness.

The success of the PASRR program in an individual State seems largely based on the State's philosophy. Some States view it primarily as an additional burden placed on the State by the Federal government and implement it as minimally as possible to meet the Federal regulations. Other States take a broader, more proactive perspective and link the assessment to services.

A properly structured PASRR process, as part of a coordinated statewide long-term care policy, can significantly reduce the number of inappropriate placements. This can be achieved by referring applicants to more appropriate settings or identifying and arranging for wraparound services to allow the

person to remain in his or her home.

A major barrier that limits the effectiveness of PASRR is the absence of alternative community placement and support options. The U.S. Supreme Court decision in *Olmstead* provides an opportunity to address this issue. As States develop their *Olmstead* plans, consumers, family members, and other stakeholders must ensure that the needs of older adults with mental illnesses are considered and included. PASRR data can document the need for community-based care with State legislators, planners, and policymakers. A more complete discussion of barriers to community-based services for older adults with serious mental illnesses follows in the next section.

## SECTION II

# Barriers to Community Integration

Moving older adults from institutions, which may have been their “home” for most of their lives, to the community presents a unique set of challenges. Until recently, nursing facility placement was the most common, and in some cases the only, long-term care option for older adults considered in many States. This was in large part due to the lack of community-based alternatives in general, and residential options in particular.

The Federal and State emphasis on children and younger adults with mental disorders—who are more mobile and visible and have had more effective advocates—has also been a factor in lack of attention to older adults. Mental health advocates for older adults have just begun to draw attention to the needs of this population and are only now beginning to convince policymakers to address these needs.

The *Olmstead* decision has helped bring to light the lack of attention States have given to alternatives to institutionalization for older adults with serious mental illnesses. This section highlights specific barriers to the development of a range of residential options, treatment, and support services that help older adults with mental illnesses leave institutional care and succeed in the community, or prevent inappropriate institutionalization. Fiscal and related Federal policy barriers are part of this discussion.

## Fiscal Barriers

Compared to general health care, mental health is underfunded in all State and Federal programs, as well as in private insurance. There is a continuing push and pull among the various stakeholders for scarce dollars that must be shared among children’s services, adult services, and services for older adults with mental health needs. As a result, older adults with serious mental illnesses often are shortchanged.

Current reimbursement and financial policies tend to favor inpatient versus outpatient care; medical versus psychological care; acute versus chronic care;

and more restrictive versus less restrictive care (Estes, 1995). In particular, the primary sources of funding for people with serious mental illnesses and for older adults, Medicaid and Medicare, respectively, offer incomplete coverage for older adults with mental health disorders. Medicaid funding is focused largely on institutional services, and Medicare coverage for mental health services is limited. Older adults with serious mental illnesses are vulnerable to being underserved in managed care arrangements.

## Medicaid

Medicaid is the largest payer of institutional care for older adults with mental illnesses. The high cost of nursing home care quickly depletes the savings of most residents, and since Medicare does not contain a long-term care benefit, most nursing home residents eventually must rely on Medicaid. In 1998, nursing home care accounted for \$44 billion of the \$174 billion Medicaid budget. Overall, Medicaid funds 46 percent of nursing home expenditures (HCFA, 2000a).

The Medicaid program is a partnership between the Federal government and State governments to pay for health care for economically disadvantaged individuals and those with disabilities, with States contributing up to 50 percent of the costs. The Federal/State Medicaid match is formula-based and varies among States. Eligibility standards and extent of covered services also vary greatly from State to State. While Medicaid enables States to use Federal funds to provide health and mental health care for low-income residents, the mandated State match makes some legislatures reluctant to add services or broaden eligibility.

Medicaid is an entitlement program, meaning that there are certain basic services (“mandated services”) that a State participating in the Medicaid program must provide when the services are deemed medically necessary for an eligible recipient’s care. Nursing facility services are a mandated service under the

Medicaid program, but Medicaid funding policies discourage the provision of specialty mental health services in nursing homes (U.S. Department of Health and Human Services, 1999).

States may elect to provide optional services, though provision of these services across the States is limited and uneven (Bartels & Smyer, 2002). The most common option for mental health services is the Medicaid Rehabilitation Option, which offers more flexibility in the services that are provided and in the types of professionals that can provide the services. The rehab option is popular with States both because of its flexibility and because of the State's ability to limit coverage to selected groups.

Home and Community-Based Services (HCBS) waivers are a Medicaid optional service that allows States to develop alternative community-based services to prevent unnecessary institutional placements and to facilitate the discharge of residents from institutions. States must demonstrate that the cost of such services would not exceed the cost to Medicaid of the covered institutional services. All States have some HCBS waivers, and most use them to serve older adults and people with physical disabilities (General Accounting Office, 1995). Few States have requested HCBS waivers for individuals with chronic mental illnesses (Lutzky et al., 2000).

## **Medicare**

Unlike Medicaid, which is a Federal/State partnership, Medicare is funded by the Federal government. Medicare is the largest funding source for health care provided to older adults. However, only 0.57 percent of total Medicare expenditures are for mental health services (Bartels & Smyer, 2002).

Within each State, Medicare contracts with a local health care insurer to administer the program. The State entity, commonly referred to as a "carrier" or sometimes an "intermediary," has significant flexibility in establishing coverage policy. Medicare reforms in recent years have increased access to outpatient services, but less than one percent of Medicare mental health expenditures are for older

adults in noninstitutional settings (Colenda et al., 2002).

Medicare beneficiaries access services through Medicare-approved health care providers. Medicare provides 80 percent payment for medically based services, resulting in a 20 percent copayment requirement. For nonmedical mental health services, such as psychotherapy, Medicare covers only 50 percent, requiring a 50 percent copayment. Approximately 14 percent of Medicare beneficiaries have no supplemental insurance and pay this copayment out-of-pocket.

Those who have supplemental insurance include those who buy it on their own, those who receive it as a retirement benefit, or those who are covered under Medicaid as "dual eligibles." Dual eligibles (those who are covered under both Medicare and Medicaid) comprise approximately 16.5 percent of Medicare beneficiaries and 19 percent of all Medicaid beneficiaries (HCFA, 2000a, 2000b).

## **Mental Health Parity**

Since virtually all older Americans participate in the Medicare program, the issue of parity (i.e., equal coverage for physical and mental health services) is of critical importance. Historically, insurance coverage in both the public and private sectors has not adequately covered mental health services.

One reason used to justify this over the years was the fear that the cost, particularly to insurance companies and employers, would substantially increase if mental health services were fully covered. Recent research, however, has shown that parity for mental health care results in negligible cost increases when care is managed (U.S. Department of Health and Human Services, 1999). Another factor was the perception that many mental health services were not really "medically necessary."

During the 1990s advocacy efforts to achieve parity for coverage of mental health services increased, leading to passage of legislation nationally and in many States. Although this was an important step forward, broad-based parity has not been

achieved. Opponents of mental health parity have successfully placed limitations and exemptions on the enacted legislation. For example, small businesses have been exempted under most plans. Employers can “opt out” if they can demonstrate that the increased cost of providing the coverage will exceed a specified percentage (Shea, 2002).

Furthermore, laws often fail to mandate mental health coverage, with parity required only if the insurance plan elects to cover mental health services. Though advocates feared that insurance plans would drop coverage of mental health services rather than provide parity coverage, it appears this has not happened, probably because the actual cost has been less than expected (Sing et al., 1998).

### **Prescription Drug Costs**

Many effective medications are available to treat mental health disorders, including some newer drugs that are less likely to have the significant side effects associated with older drugs used to treat mental illnesses. However, until recently, Medicare did not provide a prescription drug benefit. Advocates for prescription drug coverage argue that this resulted in many low-income older adults having to choose between food and other essential needs, and paying for their medications. This is a particular burden on older adults with mental health disorders.

The Medicare Modernization Act (MMA), signed in December of 2003, provides a first step towards a comprehensive Medicare pharmacy benefit. The prescription drug benefit allows Medicare beneficiaries to enroll in a prescription drug plan, with Medicare paying 75 percent of the premium. Enrollment in the prescription drug plan will begin in the fall of 2005, with benefits scheduled to start in January 2006, and prescription drug discount cards are currently provided as a transitional benefit. Despite the passage of the MMA, older adults may continue to have inadequate access to mental health drugs due to potential cost-sharing requirements and restrictive formularies. Older adults who are dually eligible for Medicaid and Medicare may actually experience increased copayments and reduced access to specific prescription drugs.

Medicare beneficiaries have had mixed reactions to the MMA. A recent survey suggests that only 26 percent of Medicare beneficiaries have a favorable impression of the Medicare drug benefit. These beneficiaries envisioned that the program would be helpful to low-income persons as well as those with high prescription drug bills, would help pay for many of the prescription drug bills, and would allow persons to choose a prescription drug plan that best met their needs. However, 47 percent of beneficiaries had an unfavorable impression of the drug benefit as they felt it did not provide enough help with prescription drug costs, was too complicated to understand, and provided too much benefit to private health plans and pharmaceutical companies (Kaiser Family Foundation & Harvard School of Public Health, 2004). Moreover, only one-third of beneficiaries thought that the interim drug discount cards were helpful. In contrast, over half (55 percent) felt that the cards weren't worth the trouble because they didn't go far enough to help with prescription costs and were too confusing (Kaiser Family Foundation & Harvard School of Public Health, 2004).

Even for individuals who have prescription drug coverage, many of the newer medications may be unavailable or too costly through their insurance plans. Some are quite a bit more expensive than older drugs. Typically, health insurers establish policies that provide financial incentives, such as discounts or penalties, including higher copays, to encourage the use of generic drugs. Some Medicaid plans may require that individuals “fail” on the older medications before being allowed to try the newer drugs. These factors limit the availability of the latest and most effective drug treatments for older adults with serious mental illnesses.

### **Managed Care**

The increasing reliance on managed care, particularly within Medicaid and Medicare programs, holds both promise and perils for older adults with serious mental illnesses. About 40 percent of Medicaid enrollees and 15 percent of the Medicare

population are in managed care plans. Estimates are that 35 percent of all Medicare beneficiaries (15.3 million people) will be in managed care plans by 2007 (U.S. Administration on Aging, 2001).

The promise of managed care is lower costs and better coordination of care, but results are mixed, especially for vulnerable populations. The Surgeon General's report on mental health notes that managed care geriatric programs and clinical case management for older people are inadequate or poorly implemented (U.S. Department of Health and Human Services, 1999). Managed care plans have been criticized for lack of the array of community support and residential rehabilitation options for people with serious mental illnesses.

Managed care organizations that bear the financial risks for their enrollees' care have an incentive to avoid older adults with serious mental illnesses, who have comprehensive, long-term treatment needs. Those plans in which mental health is "carved out" from physical health care have a difficult time coordinating care for older individuals with both medical and mental illnesses.

Clinical outcomes in managed care plans are mixed. People most likely to have negative outcomes include individuals with chronic conditions, those with low incomes who are in worse health, and older people who are frail or impaired. These characteristics also are commonly associated with older adults with serious mental illnesses (U.S. Administration on Aging, 2001). At least one observer has noted that there are "no known successful models of HMO care to severely mentally ill elderly people" (Knight & Kaskie, 1995).

## **Service System Barriers**

Older adults seeking mental health services—especially community-based services—often encounter service system barriers that undermine both the quality of and access to effective services. Some of these barriers are directly related to the funding problems described in the previous section, but others

are inherent in the structure and interaction of the service systems themselves.

### **Fragmented Systems of Care**

The system of care for older adults with mental disorders has been described as a "non-system of care," plagued by irrational incentives and multiple access barriers" (Colenda et al., 2002). The emphasis is on cost reduction rather than on systems integration. A fragmented and underfunded system of care is hardly ideal for providing even a safety net for fragile individuals who are attempting to move to a less restrictive setting and live more independently.

Older adults with serious mental illnesses are especially vulnerable to falling through the cracks of a fragmented system of care. They deal with multiple and distinct care systems—including medical care, long-term care, mental health services, aging network services, and dementia care services—each with its own operating principles and reason for being (Knight & Kaskie, 1995). No one agency is responsible for coordinating care for older adults with serious mental illnesses.

In an era of increasing needs and decreasing resources, mental health and aging services programs are under enormous economic pressure to compete for funds and to cut costs by dealing with existing clients only. Mental health providers focus on people with mental disorders, and aging services program focus on older adults. This approach is not conducive to caring for older adults with serious mental illnesses, especially those with lengthy histories of institutional care, who require multiple, coordinated, and intensive long-term services.

Fragmentation in service delivery for older adults with serious mental illnesses is especially problematic in two areas: lack of coordination with primary care providers and lack of discharge planning. Each is discussed in brief below.

#### **Lack of Coordination with Primary Care**

More than half of older people who receive mental health care are treated by their primary care

provider (U.S. Administration on Aging, 2001). This may be especially true for older adults who are members of minority groups.

The advantages of primary care for older adults include proximity, affordability, convenience, and coordination of mental and medical disorders. Also, older adults feel less stigmatized seeking help from a primary care provider than from a mental health provider (U.S. Department of Health and Human Services, 1999; Colenda et al., 2002).

However, the rate at which primary care providers identify mental disorders in older adults is extremely low. Primary care practitioners receive insufficient training in mental health and in geriatric assessment and care, and they frequently attribute psychiatric symptoms to aging or to physical disorders (U.S. Administration on Aging, 2001). Assessment is difficult, particularly when medical disorders mimic or mask psychopathology (see “Clinical Barriers” in this section).

Primary care providers have been criticized for relying excessively on medications to treat their older patients with mental disorders, for spending little time on counseling, and for making few referrals to mental health professionals when a mental disorder is identified (Estes, 1995; Colenda et al., 2002). New models of cooperation between primary care and mental health services are discussed in the final section of this report.

### **Lack of Discharge Planning**

Psychiatric hospital stays are increasingly shorter, and, ideally, individuals should be prepared for discharge beginning at admission. Unfortunately, shorter stays mean that some individuals with serious mental illnesses are released before their symptoms are adequately stabilized. In the absence of a good discharge plan, even individuals who are ready to leave are at risk for repeat institutionalization and possible homelessness.

A lack of coordination between the hospital and other community-based providers to ensure appropriate housing, treatment, income, and supports

may be especially problematic for older adults who have been institutionalized for lengthy periods of time and who have come to depend on the hospital or nursing home to meet all of their daily needs. Skills such as food shopping and preparation, personal grooming, and paying bills may be unknown or forgotten. These deficits can impede life in the community. Effective discharge planning as a prevention strategy is discussed in the next section.

## **Lack of Appropriate Residential and Community-Based Services**

Older adults with serious mental illnesses want and need the same types of services and supports that their younger counterparts desire. In a study of older adults with serious mental illnesses in Thunder Bay, Ontario, participants cited the need for a meaningful, productive life; safe and secure housing; social networks; and individualized programs (Tryssenaar et al., 2002). Lack of such services impedes their recovery and their ability to live successfully in the community.

### **Lack of Services**

While effective housing and service programs with well-qualified staff are available in certain locations, they remain the exception rather than the rule. In general, community mental health providers are not trained or funded to address the specific issues that face many older adults with mental health problems, including the need for housing, transportation, nutritional meals, and care for medical illnesses. Older adults represent 13 percent of the U.S. population but receive only 6 percent of community mental health services (U.S. Administration on Aging, 2001).

Many Community Mental Health Centers report no aging-specific programs or staff trained in geriatrics, and only 23 percent of CMHCs report having formal relationships with Area Agencies on Aging (Knight & Kaskie, 1995). Although few older adults present for specialty mental health services, in part due to stigma, only 15 percent of community mental health providers named older adults as a target group for outreach (Estes, 1995).

These factors are often further compounded by many older adults' lack of skills and experience at organizing the resources needed to meet their needs. Case management, a key service for addressing these needs, is a Medicaid optional service that States can choose to provide. However, in nearly all States, case management is either used for younger mental health consumers or is limited to far fewer individuals than could benefit from the service.

**Lack of Access to Services.** Even when services are available, older adults with serious mental illnesses may not have access to them. Problems with access to adequate and appropriate mental health services were cited as one of the major concerns of the President's Commission on Mental Health Subcommittee on Older Adults (Bartels, 2003). Many older adults no longer drive or have access to a car; others may be afraid to take public transportation (H. Gardiner, personal communication, November 12, 2002). Older adults who are especially frail may need to rely on special transportation services that are too expensive.

Access problems are compounded for older adults living in rural areas. Lack of trained providers and access to the newest treatments and medications are barriers for rural residents with serious mental illnesses, and older adults often must travel long distances to receive services.

Lack of ethnically diverse staff in both mental health and aging programs is a further barrier to treatment and support for older adults. The U.S. U.S. Administration on Aging (2001) reports an insufficient number of mental health professionals from ethnic minority groups. Language and cultural barriers may lead to inadequate services.

### **Lack of Housing**

Most older adults with serious mental illnesses prefer to live independently in their own homes, and many do so successfully when they have access to a range of services and supports (Bartels, Miles, et al., 2003). Residential options will continue to be needed for some older adults with serious

mental illnesses—especially for individuals with comorbid medical problems, physical limitations, developmental disabilities, and limited personal living skills. These individuals require some level of onsite support, but not the level of care provided in nursing facilities. While there is a growing understanding of the importance of individualized housing, scarce resources mean that a full range of options is rarely available.

In addition to nursing homes, many older adults with psychiatric disorders reside in other long-term care settings, including assisted living facilities, adult foster care homes, and board and care facilities. These facilities vary in quality and oversight. Those that have caring and well-trained staff and that are well-connected with area resources are excellent for that minority of people who prefer to live in a group setting. However, a lack of options and limited finances means that many individuals who would much rather live on their own must live in congregate, often low-quality facilities. Brief descriptions of several of these types of facilities follow.

**Assisted Living Facilities.** Assisted living facilities for older adults who need support to live in the community but who do not require institutionalization provide an assortment of long-term care options and services. Data from 1996 suggest that 30,000 to 65,000 assisted living facilities were operating in the United States; currently over a million older people reside in assisted living facilities (American Association of Homes and Services for the Aging, 2002). Most such facilities provide housing, meals, personal assistance, and medication reminders (Becker et al., 2002).

Prevalence rates of psychiatric disorders in assisted living facilities have not been systematically documented, but available data suggest that these settings are likely to house substantial numbers of older adults with cognitive impairment disorders, depression, and other psychiatric disorders. Most States license assisted living facilities but do not require them to screen for psychiatric illnesses or treat mental disorders, suggesting that there is substantial

unmet need for treatment (Bartels, 2001; Becker et al., 2002).

In response, an increasing number of States are licensing assisted living facilities to provide mental health services. In Florida, for example, limited mental health licensure is required for facilities that admit three or more individuals with a mental disorder (Becker et al., 2002). However, without reimbursement for increased costs, many of these regulations will be unenforceable. Individuals living in homes that are not eligible for or choose not to apply for special licensing are at risk of being displaced and possibly institutionalized (Becker et al., 2002).

Medicaid provides limited resources for some older adults with mental illnesses residing in assisted living facilities. As of 2001, some services provided in assisted living facilities were covered under Medicaid in 39 States. However, as with most optional Medicaid services, reimbursement policies differ among States. In addition, although a State Medicaid program may support several reimbursable services, assisted living facilities are not required to provide all reimbursable services to their residents (Mollica, 2001).

With typical monthly rates of \$2,000 to \$4,000, many assisted living facilities are unaffordable for individuals with low incomes (American Association of Homes and Services for the Aging, 2002). Furthermore, residential services in assisted living facilities do not qualify for Medicaid reimbursement.

**Adult Foster Care.** Adult foster care ranges from residence in private homes to boarding houses or communal living arrangements. Originally developed for individuals with developmental disabilities, such programs meet the transportation, physical care, and other daily living needs of older adults unable to manage independently. These facilities are often seen as a less intensive alternative to nursing homes for older adults who are less impaired than typical nursing home residents (Mehrotra & Kosloski, 1991).

Generally, adult foster care costs less and restricts life less than does institutional care. Often funded through a contractual agreement with the State, the availability of adult foster care varies across the country. In addition, there is little consensus regarding program descriptions, consumers, goals, or measures of success across programs.

**Board and Care Facilities.** A substantial number of individuals with mental illnesses who have histories of treatment in State hospitals live in board and care homes, which provide residential services to individuals with limited financial means. These modest, privately owned facilities are often located in low-income communities and offer low-cost, long-term care services. Tenants typically receive a bed and regular meals; they may also receive laundry service, but little else.

Proprietors charge residents the amount of their monthly Social Security check, minus a small amount of spending money. Up to 25 percent of older adults living in board and care facilities have a diagnosable mental illness (Hopp, 1999); however, there is substantial regional variation. For instance, a recent report indicated that 83 percent of adult home residents in the Brookhaven complex in New York had a history of mental illness (Meyers, 2001). An investigative report by the *New York Times* called New York City adult homes “little more than psychiatric flophouses” (Levy, 2002).

Board and care facilities include nonmedical, community-based residential settings, such as group homes, adult homes, domiciliary homes, personal care homes, and rest homes (General Accounting Office, 1989). This setting is largely unregulated, and access to care is highly variable (Herd, 2001). Due to the minimal oversight, the quality of these facilities depends to a large extent on individual proprietors. For example, severe problems in the quality of psychiatric and general health care for individuals with serious mental illnesses in boarding homes in inner city New York was cited as a cause of high rates of mortality for this vulnerable population (Levy, 2002).

## Lack of a Qualified Workforce

A consensus statement published in the *Archives of General Psychiatry* (Jeste et al., 1999) referred to the “upcoming crisis in geriatric mental health.” A primary concern is the current and future shortage of mental health professionals in general, and specifically those trained to work with older adults (Bartels, 2003; Van Citters & Bartels, 2004a).

The number of trained geriatric mental health specialists is insufficient to meet service demands. For example, there are approximately 2,425 board-certified geriatric psychiatrists and 200 to 700 geropsychologists. However, estimates suggest that at least 5,000 professionals are needed in each specialty to begin to address service demands (Jeste et al., 1999).

Many rural areas are already underserved by mental health professionals; those also specializing in working with older adults may not be available within hundreds of miles. For example, of Indiana’s 92 counties, 64 counties did not have a psychiatrist, 23 had no clinical psychologist, and 4 did not have a clinical social worker. Three counties had none of these professionals at all, according to a survey by the Indiana Division of Mental Health and Addiction in 1999. The situation in Indiana is not unique. Other States are facing similar shortages, particularly as budget cuts make it even more difficult to draw trained geriatric mental health professionals to rural areas.

While other countries, most notably Great Britain and Japan, have created significant numbers of geriatric departments in medical schools, the United States has not. An Alliance for Aging Research (2002) report indicates that only 3 out of 144 medical schools have geriatric departments. The United States has few Centers on Aging, and funding for Geriatric Education Centers has been reduced in recent years. This report also addresses current and future shortages of nurses, psychologists, pharmacists, physical therapists, and social workers with geriatric training.

The current and projected future shortage of mental health professionals points to the need for

adequately trained paraprofessionals and other direct care workers. There is also rapid turnover among these workers, who play a central role in direct service to older adults with mental illnesses. Workers are undertrained, underpaid, and often work under stressful conditions. A combination of Federal and State policy changes and additional resources will be necessary to address this problem. For all these reasons, volunteers will play an increasingly important role in the care of older adults.

## Clinical Barriers

A significant number of older adults with mental illnesses and substance abuse disorders remain unrecognized and untreated. The U.S. Administration on Aging (2001) recommends routine screening for cognitive, behavioral, and emotional disorders by health care providers in an effort to assure access to quality mental health care. Other authorities also recommend annual or regular screening for alcohol and substance abuse (CSAT, 1998).

Screening of older adults for mental illnesses is complicated by their comorbid medical conditions, their tendency to express somatic complaints rather than psychiatric symptoms, and their preference for treatment in primary care rather than mental health settings (U.S. Department of Health and Human Services, 1999). Screening of older adults in institutions may focus on disabilities rather than strengths and may result in inappropriate treatment. Furthermore, failure to ascertain other potential support information (i.e., community, family) may result in premature long-term care facility placement when informal caregivers could support individuals in the community for a greater length of time.

Screening alone, in the absence of specific training for physicians and adequate services to which they can refer patients, is not enough. For example, research shows that screening for depression or screening plus a psychiatric interview results in an increased number of recognized cases of depression and increased prescriptions for antidepressants, but does not relieve patient distress (Bartels, Coakley, et al., 2002; Oxman & Dietrich, 2002).

Moreover, the U.S. Preventive Services Task Force (2002) recently recommended screening adults for depression, but only in clinical practices that have systems in place to assure accurate diagnosis, effective treatment, and follow-up. However, systems to ensure effective care are rarely in place. Several large studies that are examining the provision of mental health services to older adults in primary care are detailed in the last section of this report.

## **Societal Barriers**

Officially designated the “Decade of the Brain,” the 1990s were dedicated to enhancing public awareness about brain disorders and the benefits of brain research. Focused attention on mental health issues by the Surgeon General of the United States, combined with research and public awareness activities initiated by the National Institute of Mental Health, the Library of Congress, and SAMHSA worked to reduce the stigma of mental illnesses. However, stigma and discrimination, as well as a lack of attention to prevention research and services, remain significant barriers for older adults seeking mental health services.

## **Discrimination and Stigma**

Older adults with serious mental illnesses face discrimination and stigma both for their mental health disorders and for their age. Ageism can reveal itself in benign neglect. For example, family members and physicians may view depression as a normal part of aging, or believe that a loved one or patient is too old to be treated for a substance abuse disorder. Or ageism may be more overt, as when older individuals are viewed as being no longer able to be productive on the job (U.S. Administration on Aging, 2001).

People with mental illnesses frequently are stigmatized by myths, sometimes perpetuated by media portrayals of mental illness, which view them as dangerous or incapable of recovery. Bias and fear, based on stigma, exists among families, neighborhoods, and society, as well as professionals and other service providers. Such attitudes can

complicate successful community integration (U.S. Department of Health and Human Services, 1999).

Older adults themselves may internalize these attitudes and may fail to seek treatment for mental health problems. Fear of being labeled “insane,” of losing their independence, and the perceived shame associated with mental illness are all powerful incentives to avoid treatment, or even to learn about mental health issues. This may be especially true for older adults who came of age when treatments for mental illnesses were less effective than today and often regarded with fear (U.S. Administration on Aging, 2001).

The National Institute of Mental Health estimates that as few as 1 in 10 older adults with depression receive treatment (Lebowitz et al., 1997; National Institutes of Health, 1992). The significantly higher rate of suicide among those over the age of 65 has been partially attributed to older adults’ reluctance to seek mental health treatment (U.S. Department of Health and Human Services, 1999).

Finally, since deinstitutionalization began, the attitude of Not In My Back Yard (NIMBY) has influenced the development of community-based programs. Restrictive covenants, city ordinances, single-family zoning, State laws governing disability housing, and organized neighborhood protests are some of the ways communities act on their fears. Research has shown that concerns about property values, crime and violence, and public nuisances are based largely on misinformation and myths (U.S. Department of Health and Human Services, 1999).

## **Insufficient Attention to Prevention**

It is less expensive and more humane to keep people from becoming ill than it is to treat them when they become sick. However, prevention research in mental health is in its infancy, and most efforts have focused on children and adolescents. The need for prevention of mental disorders and excess disability that may result from such disorders among adults and older adults is increasingly recognized. Some prevention efforts are described in the next section.

# SECTION III

## Prevention

Contrary to popular stereotypes of old age as a time of increasing cognitive decline and functional impairment, studies have shown that older adults are psychologically robust, resilient, and capable of change, even in the face of physical, emotional, and economic losses (Waters, 1995; U.S. Administration on Aging, 2001). For people with serious mental illnesses, old age may be a time of increasing acceptance and ability to cope with lifelong mental health disorders (Cohen, 2000).

Increasing the protective factors that mitigate against the development or recurrence of mental health disorders and decreasing the risk factors that lead to mental health decline and possible institutionalization are both possible and appropriate. The Surgeon General's report on mental health urges a broad view of prevention as the development of interventions for "reducing the risk of developing, exacerbating, or experiencing the consequences of a mental disorder" (U.S. Department of Health and Human Services, 1999, p. 341).

### Risk and Protective Factors

Prevention research focuses on the interrelated concepts of risk and prevention. Risk factors are "those characteristics, variables, or hazards that, if present for a given individual, make it more likely that this individual, rather than someone selected from the general population, will develop a disorder" (Mrazek & Haggerty, 1994, p. 6). Protective factors are those characteristics and variables that guard against a negative outcome. Taken together, "the combination of risk and protective factors affects the individual's susceptibility to the development of mental disorders" (Smyer, 1995).

Risk factors for older adults include relationship loss and bereavement, chronic illness and caregiver burden, social isolation, and loss of meaningful social roles (Mrazek & Haggerty, 1994). Older adults may experience chronic pain, physical disabilities, and handicapping conditions; impaired self-care; and reduced coping skills (CSAT, 1998). Protective

factors at this time of life include social support in the form of family, peers, and informal relationships; more formal support groups; health and social services such as respite care; and opportunities for new, productive social roles (Mrazek & Haggerty, 1994).

The Surgeon General's report outlines a comprehensive strategy for prevention focused on older adults. The report calls for prevention of depression and suicide, prevention of relapse/recurrence (treatment-related prevention), prevention of excess disability, and prevention of premature institutionalization (U.S. Department of Health and Human Services, 1999). The balance of this section is based on this taxonomy.

### Prevention Activities

#### Prevention of Depression and Suicide

Depression in older adults is a serious public health concern. Prevalence rates range from 8 percent to 20 percent in community settings and up to 37 percent in primary care (U.S. Department of Health and Human Services, 1999). In addition, one half of older adults new to nursing homes are at increased risk for depression, and major depression in nursing home patients increases the risk of death by 59 percent, independent of other physical health problems (U.S. Department of Health and Human Services, 1999).

Furthermore, more than two-fifths of older adults with schizophrenia show signs of clinical depression (Cohen, 2000). A recent study in the *American Journal of Geriatric Psychiatry* (Lyness et al., 2002) revealed that depressive states that fall below the clinical threshold are frequent and persistent in older adults and are associated with distress and disability. Investigators also found that individuals who initially had less severe forms of depression were more likely to develop major depression than individuals who had not been depressed.

Risk factors for late-life depression in older adults include female gender, widowhood, physical illness or impaired function, heavy use of alcohol, and absence of a support network (U.S. Department of Health and Human Services, 1999; Smyer, 1995). Depression in older adults is associated with increased health care use, poor quality of life, and risk for suicide.

Both support groups and peer counseling have been shown to be effective for older adults at risk for depression. Bereavement support groups, in particular, can help improve mental health status for widows and widowers (Mrazek & Haggerty, 1994; U.S. Administration on Aging, 2001; U.S. Department of Health and Human Services, 1999). Evaluation of a program run by the American Association of Retired People (AARP) called the Widowed Persons Service, which pairs new widows with a widow who can provide emotional support and practical assistance, found that women receiving the intervention recovered more quickly and experienced fewer depressive symptoms than those who did not participate (U.S. Administration on Aging, 2001; Waters, 1995).

Peer counselor prevention focuses on early detection, or self-detection, and referral to care before the illness becomes acute. The Skagit Community Mental Health Center in Washington State has published a training manual for older adult peer counselors. The use of older adult consumer counselors provides a unique opportunity for older consumers to share with their peers, who will talk to them from firsthand experience about the symptoms of mental illnesses and substance abuse disorders and the fact that treatment works.

## **Prevention of Relapse/Recurrence**

What the Surgeon General's report terms "treatment-related prevention" involves prevention of relapse or recurrence of an underlying mental disorder. Adults with late-onset depression (over the age of 60) have a relatively high rate of recurrence (U.S. Department of Health and Human Services, 1999). Individuals who have experienced serious and

persistent mental illnesses throughout adulthood may have a substantial residual disability.

Older adults with serious mental illnesses are at risk for medication side effects and adverse reactions. As discussed previously in this report, older adults metabolize medications differently, and they frequently take multiple prescription and over-the-counter medications, often for comorbid medical illnesses. Efforts to monitor medication use and compliance on the part of older adults can help prevent medication side effects from being construed as psychiatric symptoms that require nursing home or hospital care.

## ***Discharge Planning***

Older adults with mental disorders are at risk of relapse during the transition from hospitals to the community if their symptoms have not been sufficiently stabilized, or if they leave without an adequate discharge plan. An effective discharge plan will include an appointment for community mental health provider follow-up, medications to last until the follow-up appointment, other social and transportation needs, and access to these services and supports. Ideally, community providers will have been involved throughout the treatment process and will be prepared to offer continued aftercare and support services.

For some individuals, especially those who have been institutionalized for lengthy periods of time, skills training will be a necessary component of preparation for independent living. The activities of an independent daily life are taken for granted by most adults. However, for individuals with serious mental illnesses who have depended on an institution to meet all their needs, skills for daily living such as shopping or paying bills may need to be relearned or learned for the first time.

In addition, older adults leaving institutions may need to make the transition slowly, perhaps moving to a group setting before being able to live on their own. Careful assessments can determine which individuals need to be moved into independent living gradually so they can practice daily living skills.

## **Prevention of Excess Disability**

Many older adults with severe and persistent mental disorders are more functionally impaired than would be expected according to the stage or severity of their disorder (U.S. Department of Health and Human Services, 1999). Medical, psychosocial, and environmental factors interact to cause excess disability. For example, depression leads to a greater degree of impairment in individuals with Alzheimer's disease (U.S. Department of Health and Human Services, 1999).

Helping older adults with mental disorders negotiate a range of needed services and supports may help reduce or forestall functional impairments that are a risk factor for unnecessary or premature institutionalization. Research shows that along with a lack of available family members, deficits in activities of daily living and instrumental activities of daily living are the most uniquely predictive of nursing home placement (Bartels et al., 1997).

## **Prevention of Premature or Unnecessary Institutionalization**

Some older adults with serious mental illnesses may need nursing home care or psychiatric hospitalization during the course of their illness. However, most older adults and their caregivers prefer to delay institutional care or prevent it altogether. Because caregiver distress is a significant risk factor for institutionalization, programs and services aimed at relieving caregiver burden can delay or prevent out-of-home placement for older adults with mental disorders.

### **Caregiver Interventions**

Often, the presence of a supportive family member is the only thing standing between an older adult and an institution. As noted previously, some 13 million individuals in this country provide unpaid care to their older relatives, and many of these caregivers are older themselves (U.S. Department of Health and Human Services, 1999). Support for caregivers is a critical activity that can prevent

inappropriate institutionalization and help older adults make the transition to community living.

To receive and benefit from this support, caregivers need to know when they need help, what kind of help to ask for, how to ask, and whom to ask (Mittleman, 2002). Research has shown that psychoeducational interventions and problem-focused counseling can decrease caregiver burden and depression and can delay admission of their elderly family member to a nursing home (Doody et al., 2001).

For example, results of the NYU Spouse Caregiver Intervention Study revealed that enhancing caregiver skills and access to support delayed nursing home placement by an average of 329 days, particularly in the early to middle stages of dementia when nursing home placement is the least appropriate (Mittleman et al., 1996). Similar results were found in a 2-year nurse case management intervention, which found lower rates of institutionalization compared to those in the control group, but the benefits diminished over time (Eloniemi-Sulkava et al., 2001). In general, interventions for caregivers that are individualized and intensive have proven more effective than less potent and focused interventions (Bourgeois et al., 1996).

States receive support for caregiver initiatives under the National Family Caregiver Support Program, established as part of the Older Americans Act Amendments of 2000 (Public Law 106-501). The program calls for States, working in partnership with Area Agencies on Aging and community service providers, to offer five basic services for family caregivers, including

- Information to caregivers about available services;
- Assistance to caregivers in gaining access to supportive services;
- Individual counseling, organization of support groups, and caregiver training to help caregivers make decisions and solve problems related to their caregiving roles;
- Respite care to enable caregivers to be temporarily relieved of their caregiving responsibilities; and

- Supplemental services, on a limited basis, to complement the care provided by caregivers.

The program is funded based on a congressionally mandated formula and is administered by the U.S. Administration on Aging in the U.S. Department of Health and Human Services. Approximately \$113 million was allocated to States in fiscal year 2001. More information is available from State Agencies on Aging or from the U.S. Administration on Aging Web site at [www.aoa.gov](http://www.aoa.gov).

### **Respite Care**

Respite care, recognized as a key service by the National Family Caregiver Support Program, gives family caregivers a much needed break from the day-to-day responsibilities of caring for an older adult with serious mental illness. The most frequently requested and used form of respite care is in-home care, which can be provided by a volunteer, home healthcare worker, or nurse (U.S. Administration on Aging, 2001).

Respite care can also be provided in a group or institutional setting such as a foster home, adult day care center (see below), or nursing home. Some models offer comprehensive services designed to provide the level of care that best meets the family's needs at the time (U.S. Administration on Aging, 2001). The most conclusive research results indicate that families find respite care valuable. Findings with regard to caregiver well-being and impact on institutionalization are mixed (U.S. Administration on Aging, 2001).

### **Adult Day Care**

Adult day care centers provide respite care for family caregivers, and social interaction, skill building, recreation, and health maintenance for the older adults they serve. Most operate during normal business hours, and individuals may attend for several days or all week, especially if their caregivers are employed (U.S. Department of Health and Human Services, 1999; U.S. Administration on Aging, 2001).

The U.S. Administration on Aging (2001) estimates that the average cost of a day at an adult day care center is less than the cost of home health nursing services and about half the cost of skilled nursing facility care.

Furthermore, there is evidence that adult day care centers are cost-effective in terms of delaying institutionalization, and that participants show improvement in some measures of mood and functioning (U.S. Department of Health and Human Services, 1999). The Surgeon General's report on mental health cites the Little Havana Activities and Nutrition Center of Dade County in Miami as an example of a social model adult day care center (U.S. Department of Health and Human Services, 1999).

### **Little Havana Activities and Nutrition Center.**

Little Havana is one of the largest multipurpose nonprofit agencies in the Nation, providing 70 different health, mental health, and social services to hundreds of older people annually through 21 community centers. Health services are delivered at nutrition centers, senior centers, congregate meal sites, and four adult day health care centers, among other programs. Specific services for older adults with mental illnesses include mental health, health, social, nutritional, transportation, and recreational services. Little Havana serves the largely Cuban population of South Florida. Through consultation with families, consumers, and identified service providers, Little Havana programs and services are able to reduce admission and readmission rates to nursing homes and psychiatric facilities (U.S. Department of Health and Human Services, 2002).

**Hawthorn Services.** In Chicopee, MA, Hawthorn Services serves primarily older adults with mental illnesses through residential and day programs and a variety of outreach and support groups. Thirty-three people live in its four staffed residences and about 100 attend day programs at three locations. At the day centers, people participate in activities, hobbies, health checks, rehabilitation, and field trips.

Hawthorn was established in 1979 to serve older adults being moved out of a State psychiatric

hospital. Today, Hawthorn still serves many of those discharged but also other older adults with mental disorders living in the community, many of whom are at risk of institutionalization. The majority of clients, 75 percent to 80 percent, have schizophrenia; 15 percent to 20 percent have affective disorders, such as manic depression, and a smaller portion suffer from borderline personality disorders, according to James M. Callahan, Executive Director of Hawthorn.

Hawthorn has lowered the threshold for services, thereby avoiding or delaying placement in an institution. One day program serves many adults with dementia, providing the stimulation that can slow mental deterioration while giving caregivers time off. There is a support group for caregivers, often run in tandem with the early-stage dementia group to make attendance easier. Respite care and other supports help caregivers avoid the exhaustion that can speed placement of their relatives with mental disorders in a nursing home.

## **Health Promotion Activities**

Some observers exclude the notion of health promotion from the definition of preventive interventions (Mrazek & Haggerty, 1994). However, a broader public health approach includes a focus on both health promotion and disease prevention (U.S. Department of Health and Human Services, 1999). Health promotion activities may be especially appropriate for older adults, including those with serious mental illnesses, as they strive to maintain a level of health that will promote full community functioning and prevent unnecessary institutionalization.

Successful aging has been defined as the ability to avoid disease and disability, sustain mental and physical functioning, and engage with life (Rowe & Kahn, 1997). Extreme disability, including that which accompanies mental disorders, is not an inevitable part of aging (U.S. Department of Health and Human Services, 1999).

In her article “Let’s Not Wait Till It’s Broke: Interventions to Maintain and Enhance Mental

Health in Late Life,” Elinor Waters (1995), defines her belief that “the goal of preventive mental health interventions is to help older adults find pleasure and meaning in their lives, use appropriate services, and retain or assume as much control over their lives as possible” (p. 183). She notes that the best place to offer such services is “anywhere we can,” including those places where older adults feel comfortable, such as health care clinics, neighborhood centers, senior centers, community organizations, doctors’ offices, and religious and educational institutions.

## **Educational Programs**

Many mental health promotion activities are educational in nature, including the well-known program Alert and Alive, which was piloted in senior centers in different ethnic neighborhoods of New York City. The program includes a course in mental health education, followed by leadership training for older volunteers. Educational sessions are presented by guest speakers, who explain the services their agencies offer and help older adults become more comfortable with the idea of using these services (Waters, 1995).

STAYWELL, a precursor of the Alert and Alive program, was studied using a control group. Findings indicate that at 9-month follow-up, older adults who participated in the program were more likely to believe that behavior changes could impact their health, and significantly more likely to report positive changes in their health behaviors, such as engaging in regular exercise and relaxation, taking fewer medications, or abstaining from smoking or drinking (U.S. Administration on Aging, 2001).

## **Screening Programs**

The Blues: Not a Normal Part of Aging is a community education and screening program for clinical depression developed by the American Society on Aging (ASA) through grant funding from Eli Lilly Company. Information on organizing a program is available from ASA for use by churches, housing programs, nutrition sites, senior centers, and

other community organizations. The information kit includes a video on depression, depression screening instruments, information on how to involve the media, and a manual on organizing community presentations. At least one program is active in each of the 50 States.

The ASA Web site, [www.asaging.org](http://www.asaging.org), provides information on the program and three models:

- The Baylor Center for Restorative Care in Dallas, TX, has used the program since 1998 to screen older adults attending the Texas State Fair. The center has partnered with the Dallas Mental Health Association to promote the need for geriatric depression screening.
- North County Aging Services and the Minnesota Adult Day Services Association used the materials to encourage 10 adult day service organizations to develop screening programs throughout the State.
- In Somerset County, NJ, 12 agencies serving older adults have formed a coalition to address untreated depression in older adults.

## **Outreach Programs**

A recent review of the research literature supports the effectiveness of mental health outreach services to older persons with mental health needs (Van Citters & Bartels, 2004b). In particular, outreach services are likely to be effective both in reaching out to isolated older adults with mental health problems, as well as in providing effective home and community-based treatment of mental illness. In addition, senior centers and aging networks can join the efforts of other providers through collaborative outreach and recognition efforts. The Center for Older Adults and Their Families in New York City was started when a citywide geriatrics committee “identified the need to make mental health services available in natural

settings, such as senior centers” (U.S. Department of Health and Human Services, 2002, p.63).

The program, which is operated by Gouverneur Hospital, has had great success placing a staff member at a senior center. The staff member, who has a master’s degree in psychosocial rehabilitation and specialty training in geriatrics, provides assessments, counseling, and community education. The mental health professional is bilingual and bicultural to help serve the Center’s multiethnic population. The Center also provides comprehensive services at Gouverneur Hospital, including day treatment, case management, and clinic services. Staff are available to assist people in six different languages at the Center and in consumers’ homes.

## ***Prevention Recommendations***

In her review of mental health promotion and prevention activities, Waters (1995) offers a comprehensive list of recommendations that can be summarized as follows (pp. 202-205):

- Offer mental health education programs in a variety of settings that older adults are likely to frequent.
- Encourage preventive visits to mental health professionals.
- Offer educational workshops on topics such as retirement, widowhood, and change in health status.
- Increase opportunities for meaningful paid and unpaid work.
- Strengthen ties between mental health and aging services providers.
- Encourage joint efforts of physical and mental health providers.
- Train service providers in non-mental health settings.
- Strengthen public mental health education campaigns.
- Provide opportunities for older adults to develop their own programs.
- Support the work of self-help groups.
- Tailor interventions to the individuals and groups being served.

## SECTION IV

### Successful Practices

Progress in the treatment of mental disorders and in the care of older adults means that older adults with serious mental illnesses no longer must be consigned to live out their lives in institutional care. Newer and potentially more effective medications; innovative collaborations among mental health, primary care, and elder services providers; and programs that feature outreach and multidisciplinary treatment all hold promise for this vulnerable group of individuals.

This section highlights successful practices and innovative approaches for older adults in the community who have serious mental illnesses. Both program-level and system-level strategies are discussed.

#### ***Principles of Long-Term Care***

Increasingly, long-term care for older adults with serious mental illnesses is conceived of as a range of services needed to maintain an individual in the least restrictive setting possible (U.S. Department of Health and Human Services, 1999). The emphasis is on “aging in place” at home or in the community. Older adults with serious mental illnesses are recognized as *people first*.

The U.S. U.S. Administration on Aging (2001) notes that any system of care for older adults with serious mental illnesses must be based on the principles of community mental health practice, which include the following (pp. 21-22):

- Services should be accessible and culturally sensitive to those who seek treatment.
- Services should be accountable to the entire community, including the at-risk and underserved.
- Services should be comprehensive, flexible, and coordinated.
- Continuity of care should be assured.
- Treatment providers should utilize a multidisciplinary team approach to care.

In a study of community-based mental health services for older adults, researchers found that successful programs shared the following features (Knight & Kaskie, 1995, p. 237):

- All emphasize accurate diagnosis of older adults.
- All are interdisciplinary and treatment focused.
- All use active case-finding methods and community education approaches to bring clients in.
- All collaborate actively with other agencies that serve older adults.
- All deliver mental health services to older adults at home.

Researchers also found that services to older adults must be affordable and culturally appropriate. Many of these principles are highlighted in the discussions that follow.

#### ***Evidence-Based and Promising Practices***

In many ways, community-based mental health services for older adults are much the same as services for their younger counterparts. These services include outpatient psychotherapy, partial hospitalization/day treatment, crisis services, case management, and wraparound services. However, because older adults are particularly vulnerable by virtue of comorbid medical illnesses, poverty, and isolation, services such as outreach and home-based care take on special importance. Reviews of the research literature cite a significant number of evidence-based practices for older persons (Bartels, Dums, et al., 2002). Implementation of evidence-based practices was cited as one of the primary recommendations for improving the quality of mental health care for older Americans by the Older Adults Subcommittee of the President’s Commission on Mental Health (Bartels, 2003). A range of evidence-based and promising mental health

practices that meet the special needs of older adults are highlighted below.

## Outreach

For a host of reasons discussed elsewhere in this report, including stigma and a preference for treatment in primary care, older adults with serious mental illnesses often do not come to the attention of the mental health treatment system. Many older adults may not even know what mental health services are available. This means the mental health system must go to them.

Many successful programs that serve older adults feature outreach as a key service. Comprehensive outreach programs include case finding, assessment, referral, consultation, and education and training to community providers (U.S. Administration on Aging, 2001). Outreach services may include evaluation and treatment services, facilitated access to preventive healthcare services, referral to community treatment or supportive services, and the provision of services that are designed to improve community tenure. Frequently, outreach is carried out in places where older adults feel comfortable, such as senior centers, congregate meal programs, and other community settings. In addition to community-based outreach, other models have examined mental health services provided in nursing home settings (Bartels, Moak, et al., 2002) and video-based outreach to rural areas (Jones & Ruskin, 2001).

Research supports the success of outreach efforts (Van Citters & Bartels, 2004b). Outreach models often emphasize the provision of services aimed at improving psychiatric symptoms and community tenure. Outreach models developed for older adults with mental illness often involve a multidisciplinary team of providers that implement a care management protocol within a residential setting. Some outreach teams focus on assessment and referral, whereas others directly implement the treatment recommendations of clinicians on the team.

Older adults receiving outreach services have been shown to have decreased mental health symptoms and decreased incidence and length of psychiatric hospitalization (Van Citters & Bartels, 2004b; Russell,

1997). Furthermore, residents in one outreach program were more likely to receive clinical case management than individuals referred by other sources (Florio et al., 1998). In addition, outreach programs have enhanced the abilities of social workers to identify previously undetected cases of depression (Dorfman et al., 1995) and have been perceived as helpful to caregivers and individuals who make referrals to these programs (Seidel et al., 1992).

### ***The Gatekeeper Program***

One such initiative is the Gatekeeper Program, begun in 1978 by Elder Services in Spokane, WA. Gatekeepers is based on a simple idea—that those in need are unlikely to call for help. Many mental health problems emerge or may worsen in later life, a period when one-third of older adults in the community live alone. Gatekeeper programs respond with a simple practice: they use community members who deal with older adults as frontline assessors.

Utility, cable, telephone, bank, housing, and postal workers—as well as emergency medical technicians, firefighters, police, sheriffs, and others—are trained to identify older adults who may need mental health services and report these to a central information and referral office. For example, a utility worker called Gatekeepers about a 79-year-old woman, previously a faithful bill payer, who was now behind and sounded confused when contacted. In another instance, a bank manager called about a 74-year-old widower who accused the bank of stealing the money he had withdrawn just 2 days before.

After referral, a clinical case manager and nurse visit the home. They may need to do so several times to overcome a person’s suspicion and gain admission. To help keep the person at home, if at all possible, an interdisciplinary team—which usually includes a psychiatrist and a physician—develops a plan of care and meets with the person’s family.

A study of 1-year outcomes for older adults referred to the Gatekeeper Program reveals that clients had greater service needs at referral than clients referred for case management by other sources, but these differences disappeared after 1 year of service.

In addition, Gatekeeper clients were no more likely to be placed out-of-home than those referred by other sources (U.S. Administration on Aging, 2001). This program has been successfully replicated throughout the United States.

### ***Helping Elders through Referral and Outreach Services (HEROS)***

Programs based on the Gatekeepers model work well in rural areas where people can easily be overlooked. HEROS, or Helping Elders through Referral and Outreach Services, was begun in 1996 by a mental health and aging coalition in Pierce County, WA. HEROS staff screen phone referrals and pass them to a Geriatric Evaluation Outreach Services specialist, who makes a phone contact and home visit, if possible, to complete a comprehensive assessment and connect the person to appropriate services.

Sometimes the appropriate services are no services at all. In one recent incident, a HEROS worker was able to determine that an elderly woman who complained repeatedly about things missing from her apartment was indeed having repeated break-ins. Eventually, the apartment manager's son was arrested. Without this intervention, the elderly woman might have been assumed to be paranoid and placed in inappropriate services or medicated, notes Julie E. Jensen, a researcher at the Washington Institute for Mental Illness Research and Training.

Using a Federal Center for Mental Health Services Community Action Grant from 1997 to 1999, the model was replicated in 10 other counties throughout Washington State. Ms. Jensen stresses the need for mental health, aging, adult protective, police, and other agencies to form coalitions to provide and coordinate services.

### **Screening and Assessment**

Effective treatment begins with accurate screening and assessment. As previously discussed, accurate assessment of mental health and substance abuse problems in older adults is especially problematic. Collaboration among mental health providers, primary care providers, and elder services programs will help increase screening of older adults at any service door.

The accuracy of screening and assessment may be improved when clinicians are trained and supported in the use of a standardized geropsychiatric assessment and treatment planning toolkit, The Outcomes-Based Treatment Planning Toolkit for Geriatric Mental Health Services (Bartels et al., 2002; Bartels et al., in press). Developed with support from the New Hampshire Health Care Fund, Community Grant Program, and the Robert Wood Johnson Foundation, the toolkit is now a standard part of care in the public mental health system in New Hampshire and is being piloted by other States.

As highlighted in the first section of this report, the preadmission screening and resident review (PASRR) requirements of the 1987 Nursing Home Reform Act require States to assess individuals with serious mental illnesses to determine whether nursing home placement is appropriate. Conducted accurately, these assessments can divert individuals to community-based services and can also help reduce the length of nursing home stays for people with mental illnesses who require such care by identifying their needs and ensuring that these needs are met. A key to this is having an effective follow-up process.

In Indiana, for example, State nursing home licensure surveyors and Medicaid level-of-care reviewers are used for this purpose. A 1998 review of nursing home patient records, as part of a larger study funded by the Office of Medicaid Policy and Planning, found that 87 percent of the residents identified by the PASRR process as having a mental illness and requiring mental health services, were receiving some or all of the recommended services.

Indiana also uses a similar preadmission screening process for individuals with mental illnesses applying for admission to the State-funded Residential Care and Assistance Program. Applicants with a mental illness are referred to the local community mental health center for an assessment to determine if the facility is an appropriate placement. If the individual is approved for admission, the facility must, within 30 days, develop a plan of care for the individual that is reviewed and approved by the local community mental health center. The State residential licensure

agency holds the facility accountable for carrying out the plan.

## Mental Health Treatment

The good news is that people with serious mental illnesses and substance abuse disorders can and do recover, and this includes older adults as well. Many older Americans have lived with mental disorders for much of their adult lives and have become active participants in their own recovery. Those who develop late-life mental disorders can be treated effectively with both pharmacological and psychosocial approaches (Bartels, Dums, et al., 2002).

For example, the Surgeon General's report on mental health (U.S. Department of Health and Human Services, 1999) notes that treatment for depression is successful in 60 percent to 80 percent of older adults, though the treatment may take longer than it would for a younger person. Experts in the care of older adults with depression recommend combining antidepressant medication with psychotherapy, including cognitive behavioral therapy, supportive psychotherapy, problem-solving therapy, and interpersonal psychotherapy (Reynolds et al., 2002). Treatment of depression in older adults is critical because of depression's link to suicide.

Treatment for older adults with psychotic disorders, as with younger individuals, includes the use of antipsychotic medication. However, because of age-related changes in how individuals metabolize medication, physicians may need to "start low and go slow" in the use of psychoactive medication, or may need to consider tapering dosages to ameliorate side effects that affect functional performance (U.S. Department of Health and Human Services, 1999; Cohen, 2000). One of the best predictors of level of functioning in older adults with schizophrenia is level of social support (Cohen, 2000).

As with other vulnerable individuals who have serious mental illnesses, including people who are homeless and those who have co-occurring substance abuse disorders, older adults may benefit from community-based, multidisciplinary treatment in the

style of Assertive Community Treatment (ACT) teams. A review of the research finds significant support for this approach with older adults (Draper, 2000).

The Neighborhood Service Organization, Older Adult Services Unit, in Detroit operates a geriatric ACT program. Teams including a psychiatrist, nurse, and advocates are assigned a small number of clients, who must consent to the approach. Staff provide all services in the individual's community setting; assistance ranges from making sure that a person's dishes are done to seeing that he or she has taken medication. Over the past 9 years, 95 percent of clients have avoided rehospitalization, according to Paul Sabatini, Vice President for Behavioral Healthcare at Neighborhood Service Organization.

## Integrated Service Delivery

Older adults with serious mental illnesses interact with multiple providers in a wide range of settings. Current fragmented service systems leave coordination of care up to the individual, who is ill-equipped to handle this task. New models of service delivery for older adults emphasize integration between and among the various systems that provide care, including the mental health system, the aging services network, and the primary health care system.

Recent research supports the benefits of incorporating behavioral health care into medical settings (Katon et al., 1995; Katzelnick et al., 2000). This can be accomplished by using mental health teams, having a mental health specialist be a consultant to the primary care provider, or integrating mental health professionals into the primary care setting (U.S. Department of Health and Human Services, 1999).

The integration of mental health providers into the aging services network may also be effective. Researchers found that affiliation of a Community Mental Health Center with an Area Agency on Aging led to a broader range of services for older adults (U.S. Administration on Aging, 2001). Problems encountered included their separate funding streams and the different geographic areas they serve.

Mental health services can help reduce medical costs. A recent meta-analysis of the impact of behavioral medicine, psychotherapy, and psychiatric consultation on medical costs found consistent evidence for a reduction in medical costs associated with these services, with the greatest savings for patients over age 65 (Chiles et al., 1999).

Several multicenter, randomized trials are underway to test the effectiveness of different models of care for older primary care patients (Unützer et al., 2001; Bartels, Coakley, et al., 2002; Schulberg et al., 2001). They include the following:

- **The Primary Care Research in Substance Abuse and Mental Health for the Elderly (PRISMe) study** is a collaborative effort among the Federal Substance Abuse and Mental Health Services Administration, the Veterans Affairs Administration, and the Bureau of Primary Health Care. The study seeks to identify the best tools for screening and assessing older adults with mental and/or substance abuse problems within primary care settings, and to evaluate the relative effectiveness of providing mental health services in primary care settings versus referring patients to outside mental health professionals (U.S. Administration on Aging, 2001). Investigators are collecting data on the most prevalent mental and substance abuse problems experienced by older adults, measured at baseline, 3-month, and 6-month follow-ups.
- **Project IMPACT (Improving Treatment of Late-Life Depression in Primary Care)** is a multiyear study funded by the John A. Hartford Foundation in New York City and the California HealthCare Foundation in Oakland, CA. The project is testing the effectiveness of a new disease management model for late-life depression that involves the use of a clinical specialist who works closely with the patient's regular primary care physician to manage the patient's depression care. Preliminary findings reveal that the intervention, compared with

usual care, leads to reduced prevalence and severity of symptoms or complete remission (New Freedom Commission on Mental Health, 2003).

- **The Prevention of Suicide in Primary Care Elderly Collaborative Trial (PROSPECT)** is funded by the National Institute of Mental Health and is being conducted at three of the Institute's Intervention Research Centers (U.S. Administration on Aging, 2001). The study is designed to increase recognition of suicidal ideation and depression in older adults. Nurses and social workers trained as health specialists will work with primary care physicians to increase their recognition and identification of depression, offer treatment recommendations, and encourage compliance with treatment. Individuals who receive this intervention will be compared to those who receive "care as usual."

#### ***Program of All-Intensive Care for the Elderly (PACE)***

A relatively new, and very promising, Federal initiative is the Program of All-Intensive Care for the Elderly, or PACE, which was established in the Balanced Budget Act of 1997. These programs allow the pooling of Federal Medicare and Medicaid dollars into an inclusive package of services for people who are age 55 or over and meet nursing home admission criteria. The program serves as the sole source of services for Medicare- and Medicaid-eligible consumers enrolled in the program. Though not geared specifically to adults with mental illnesses, these programs serve many individuals who have psychiatric disorders (Colenda et al., 2002).

In order to participate in the program, the State Medicaid agency must add PACE to the State Medicaid Plan as an optional benefit, although Medicaid eligibility is not a requirement to enroll in the program. The State must also designate a PACE State-administering agency. This may be the State Medicaid agency or another public or private agency. The State must also determine how many Medicaid enrollees it will support in PACE and the organizations with which it will contract.

PACE services are based on consumer need rather than a list of covered services. As such, they can be more comprehensive and flexible than services covered by Medicare or Medicaid separately. PACE services must include all Medicare benefits and all services in the Medicaid State Plan, but can include additional medical and social services. Services are planned and monitored by an interdisciplinary team and are provided out of a central entity, usually some type of adult day health center, but in-home, institutional, and referral services also may be provided. PACE organizations are responsible for providing any mental health services that an enrollee requires.

Successful PACE demonstration projects may evolve into permanent programs. Currently, 24 demonstration projects and 2 permanent programs are in operation. Sixteen States have at least one project, with California, Massachusetts, and New York having the most. At present, no mental health agency has a PACE demonstration or permanent project.

### **Wraparound Services**

Rather than making an individual fit into a range of different service programs, some providers and communities wrap the necessary services around the individual. The wraparound model, effectively developed for child populations (Burns et al., 1999; U.S. Department of Health and Human Services, 1999; Goldman & Faw, 1999), is particularly well suited to an older adult population.

Several models use the concept with older adults. For example, the Simcoe County Wraparound Initiative in Canada is one example of a locale that successfully provides wraparound services to people of all ages with mental illnesses (Simcoe County Mental Health Education, 1999).

Some older adult wraparound programs emphasize the integration of primary and secondary medical and social services, prevention, rehabilitation, medication, technical aids, and long-term care (Bergman et al., 1997). Others use a gatekeeper model, such as that described above, to identify older adults who may be at risk (Raschko, 1985).

The Southwest Ontario Regional Geriatric Program's Model Project in two communities provides support for wraparound services. This model coordinates community agencies—including home care, public health, and nonprofit and private nursing services—as well as acute-care hospitals and private and nonprofit long-term care facilities, to serve older, frail adults. This model has been shown to be effective in training providers to assess older adults and address their needs in a coordinated fashion (Harris et al., 1999).

A Community Mental Health Center located in New Hampshire operates an Elders Wrap Around Team, which includes 12 regular member agencies, with an additional 40 agencies participating as individuals' needs warrant. The program has reduced client hospital admissions (from 24 to 6 within just one quarter), and reduced length of hospital stays for clients served (from 18 to 12 days), as well as significantly increased referrals to other community services (Duford, 1999).

### **Home Care**

Increasingly, the goal of most service provision to older adults has been to maintain them in their own homes, where they prefer to be. Home healthcare services grew rapidly in the past 20 years, but the Balanced Budget Act of 1997 curbed this growth by greatly restricting Medicare reimbursement to home healthcare agencies (Bruce, 2002).

Typically, home healthcare agencies provide such services as skilled nursing care, physical therapy, occupational therapy, housekeeping assistance, and social work services. An increasing number provide psychiatric homecare services, which are appropriate for those older adults with psychiatric disabilities who live in the community but have functional impairments that limit their ability to live independently (Bruce, 2002).

Home healthcare by skilled nurses may increase the likelihood that older adults with mental disorders receive care for comorbid medical illnesses. Nurses in the home may also make a more complete psychosocial assessment of their patients based on

greater knowledge of the resources available to them and the environment in which they are living.

In much the same way, in-home crisis intervention allows professionals to determine possible domestic causes for a crisis and to assess individuals before their distress is exacerbated by being sent to a hospital for evaluation.

The Geriatric Regional Assessment Team of Evergreen Healthcare in Seattle uses an interdisciplinary team approach to in-home crisis intervention and stabilization. The team provides comprehensive assessments, including mental health status, medication compliance, substance abuse, health status, social issues, and functional domains. Based on the assessment, the team refers individuals to appropriate agencies for services, and follows up to ensure that a service plan is in place and that individuals are stabilized (U.S. Department of Health and Human Services, 2002).

Unfortunately, psychiatric home care services are not reaching the people who need them. Only 2.2 percent of patients who received Medicare-reimbursed home healthcare in 1997 received mental health services (Bruce, 2002). Lack of funding for these services, lack of home healthcare staff trained in psychiatric assessment and care, and lack of referral of older adults with mental disorders to home healthcare services limit the availability of this potentially valuable service for many older Americans.

### ***Housing/Residential Treatment***

Some older adults with serious mental illnesses will not have the family or financial resources to be maintained in their own homes and may require some type of residential treatment or supported housing placement to prevent unnecessary institutionalization. Historically, mental health professionals developed housing programs with little consumer input and with few financial resources. One housing model, such as board and care homes, was often the only option for all consumers. However, research and practice have shown that a variety of residential programs must be available in communities to address the needs,

abilities, and preferences of the individuals served (Bianco & Wells, 2001).

As with their younger counterparts, older adults with serious mental illnesses can be served within supported housing settings. Supported housing features flexible, individual supports, combined with affordable housing in community settings. This approach has been extremely successful in helping many people live outside of institutions, and it receives consistently high rates of consumer satisfaction. In spite of these positive outcomes, however, there are no national guidelines or funding streams for supported housing, and States have had to patch together funding to implement various elements of this approach (Denton & Bianco, 2001).

### ***Broward County Elderly and Veterans Services Division***

The Broward County Elderly and Veterans Services Division in Fort Lauderdale, FL, promotes community living and prevents unnecessary institutionalization with a series of programs that support individuals in housing. Clients are older adults with serious and persistent mental illnesses or substance abuse, or those with co-occurring disorders. These may be living in the community or about to be discharged from South Florida State Hospital. The program serves, on average, 750 older adults a year, and 92 percent are not admitted to psychiatric in-patient care. Specific services include the following:

- **Supported Housing Case Management** helps residents being discharged from the State hospital make the move to community living. A case manager, peer counselor, and nurse form a team to help the older adult succeed in his or her new life with various services such as peer support and personal nursing care. A team member visits at least weekly, and staff is on call at all times. Recipients of services live on their own, with relatives, or in family care or group adult homes.
- **Community Case Management** serves

individuals and their families in their homes with individual case plans and other measures to promote integration.

- **Intensive Case Management** helps older adults who are at risk of or awaiting institutionalization. A team of a case manager and peer counselor meet frequently with the person to stabilize his or her situation and promote community living. At commitment hearings, the team often succeeds in having the person returned to community life.
- **The Substance Abuse Program** provides prevention, treatment, and aftercare to older adults. Individual counseling is provided at people's homes and, along with group counseling, at community settings, such as a senior housing complex or a social service agency that serves meals.

The program's philosophy is the reason for its success, notes Director Stephen Ferrante. "The principle is for people to be living in housing of their choice and having the support to do so," Mr. Ferrante says. "Not one of the 42 people discharged from the State hospital that we helped has had to be re-institutionalized. We help people age in place and in a manner that deters institutionalization."

### **Community Opposition to Housing**

Community opposition is less of a concern with supported housing, which by its nature involves the use of regular, scattered-site housing in the community. For other types of residential alternatives, providers need to educate community stakeholders and involve them in the planning process. Sharing information on program components, who will be served, what can be expected, and whom to contact if there is a concern can greatly ease the transition of older adults with mental illnesses into a neighborhood. Programs must conform to community standards, and staff must be prepared to help residents become accepted community members.

To combat the NIMBY problem in Tennessee,

the Department of Mental Health and Developmental Disabilities Office of Housing systematically and effectively worked upfront with communities, asking for input and providing information about planned group residences. They dispelled myths about disruptive behavior of residents and lower property values. The results have been well worth the efforts. After 2 years, the overwhelming majority of community members agreed that group home residents have been good neighbors, that they had experienced no problems, and that property values had not dropped (Tennessee Department of Mental Health and Developmental Disabilities, 2001).

### **Peer Support and Consumer-Provided Services**

As noted in the prevention section, some older people find support groups and peer counseling more acceptable than other forms of treatment. Support groups allow participants to be both recipients and providers of assistance (Schneider & Kropf, 1992), and they enable supportive relationships to develop. They offer relief and problem-solving opportunities to participants who can normalize their problems (Lieberman, 1993).

Peer support can ready participants who lack the judgment, desire, and capacity to call for help to access treatment services (Rogers et al., 1993). Research supports the effectiveness of peer support programs for older adults that are focused on addressing depression and other needs associated with loss. In a 1-year study of peer support groups for older adults with losses, Lieberman and Videka-Sherman (1986) reported that self-help groups improved mental health status, whereas those in the control groups showed deterioration in most mental health indicators. Yet, a lack of consistency among the various studies regarding intervention conditions makes it difficult to define the extent of effectiveness, or specific components that make these interventions successful (Lieberman, 1993; Stroebe & Hansson, 1993).

### **Geriatic Peer Advocacy**

Geriatic Peer Advocacy serves older adults

with mental illnesses in several neighborhoods in Brooklyn, NY. The city-funded program is operated by the Baltic Street Mental Health Board, a consumer-run mental health organization established to serve patients leaving South Beach Psychiatric Center. Of 90 employees in 16 programs, 83 are mental health consumers. Baltic Street Mental Health operates various jobs, housing, educational, and support programs.

Geriatric Peer Advocacy offers services to older adults with mental illnesses that include information and resources on entitlements, transportation, housing, legal help, and other needs; support and help in obtaining those services; peer support groups; and workshops on recovery and self-help. All services are free and offered based on consumer request. Founded in 1996, the program serves about 50 people a year.

Outreach is a significant part of the geriatric program; however, once older adults enter the program, another challenge is to motivate them. “There’s a sense that people don’t want to be empowered,” says Isaac Brown, Director of Advocacy and Housing at Baltic Street. “It is very difficult to give older adults a sense of power.”

In its outreach and other programs, Baltic Street staff work alongside professional mental health and other workers who serve their clients. Geriatric Peer Advocacy workers conduct presentations at adult and group homes, health fairs, senior centers, churches, and other community organizations. The program runs peer support groups at its offices and also at an outpatient psychiatric clinic.

## **Consumer Involvement and Empowerment**

To help empower older adults with serious mental illnesses, consumer participation in program design and operation is vital. All services must be appropriate for age, culture, and gender. The well-known tenet of the mental health consumer self-help movement, “nothing about us without us,” applies equally to older adults with serious mental illnesses.

In recent years, self-help and advocacy organizations led by mental health consumers have

become visible and effective. Likewise, organizations comprised of older persons, most notably AARP, are known and respected, and bring important issues to national attention. Until recently, older adults with serious mental illnesses have lacked such a national forum, but a new and exciting initiative is bringing together older adults who are mental health consumers to educate researchers, policymakers, and the general public about their strengths and their needs.

### ***Older Adult Consumer Mental Health Alliance***

The recently formed Older Adult Consumer Mental Health Alliance (OACMHA) is an organization of older mental health consumers who exemplify self-advocacy among older adults with mental health needs. Funded through grants from the Federal Center for Mental Health Services and the Judge David A. Bazelon Center for Mental Health Law, the organization’s belief in the power of “our own voice” has been demonstrated at several national conferences held since the initial planning meeting in 1998.

In 2002, OACMHA established a Washington, DC, office and hired its first executive director. The mission statement of the Alliance is “to improve the quality of life of older persons affected by mental illness, and their family caregivers, by promoting through advocacy and public education, the development of accessible, affordable, and age-appropriate mental health services.”

Alliance President John Piciatelli of Washington State and Vice President Hikmah Gardiner of Pennsylvania provide evidence of what older advocates can accomplish as they speak out about the barriers to community mental services and what can be done to address them. Alliance members and their supporters were instrumental in having the needs of older adults addressed by the President’s New Freedom Commission on Mental Health, which was charged with developing an action plan for investing and coordinating Federal, State, and local resources to serve people with mental disorders.

“Don’t count me out,” is the message that Alliance

members will take around the country, Ms. Gardiner says. She says the group is concerned about such issues as the inappropriate placement of older adults with psychiatric disorders in nursing homes; lack of training for staff in nursing homes and in community settings, especially for primary care providers who prescribe psychotropic drugs; and the stigma that attaches both to older adults and to those with mental illnesses. OACMHA will spread its message of hope and recovery through support for legislation, education, fundraising, and a national membership drive, Ms. Gardiner notes.

## Cultural Competence

The Surgeon General's Report on *Mental Health: Culture, Race, and Ethnicity* (U.S. Department of Health and Human Services, 2001) said it succinctly, "Culture counts." The report notes that members of minority groups have less access to mental health services than whites, and the treatment they do receive is often of poorer quality. As the number of older adult members of minority groups increases, so, too, does the need to provide culturally adapted and age-appropriate services that are meaningful to them.

Stigma, language barriers, and lack of ethnically diverse and age-appropriate staff are barriers to appropriate care for older adults with serious mental illnesses. Mental health services for these individuals should be delivered by staff educated or trained in age-appropriate assessment and interventions, as well as lifespan developmental and cultural issues. Age-appropriate and culturally sensitive protocols and outcome measures should be required of every provider, perhaps as a contract requirement. Such practices have been shown to increase access rates for older adults (U.S. Department of Health and Human Services, 2001).

The Kit Clark Senior Services program in Boston provides a full array of services to older adults with mental illnesses who are multiethnic and multilingual. Services include assessment, treatment planning, case management, home care, referral services, home-delivered meals, transportation, housing, home repair, health education, and services for people who

are homeless. The program helps instill self-respect and dignity in the individuals it serves by addressing needs in a culturally sensitive manner and treating the whole person.

A hallmark of Kit Clark's success is community collaboration. The agency has built a supportive network of agencies that cross-refer, including the Area Agency on Aging, home care programs, hospitals, area churches, and others (U.S. Department of Health and Human Services, 2002).

## System-Level Strategies

Complex cross-system problems call for new ways of doing business. Clearly, no one service system is equipped to address all of the needs of older adults with mental illnesses. Effective services require coordination and collaboration between and among providers of aging, health, substance abuse, and other services, in addition to mental health services. However, coordination and collaboration are often difficult because of "turf" issues, funding inflexibility and shortages, and rules and regulations that conflict. Coalitions at the national, State, and local levels have evolved to address the need for systems integration.

Community coalitions can be instrumental in bringing disparate resources together to provide coordinated services. Effective coalitions bring together providers and consumers in the areas of mental health, substance abuse, primary care, and aging to identify available resources and gaps. Through reaching out to one another, coalition members build trust across agency and community lines, resulting in cooperative efforts to enhance service availability and accessibility.

Successful collaboration includes communication and cross-training among agency heads and frontline workers. Memoranda of understanding, contracts, or other working agreements can be created that identify agency roles in providing services to individuals, and management information systems can be designed to allow providers to share certain records and information while protecting client privacy.

Recognizing the need to reduce the numbers of older adults with dementia or mental illnesses in State hospitals and improve community-based services for these individuals, the Alabama Department of Mental Health and Mental Retardation carried out a three-phase plan to (1) create a Bureau of Geriatric Psychiatry within the Department; (2) develop a continuum of care within the community to provide housing, services, and support for older adults with dementia or mental illnesses; and (3) open a tertiary care hospital to facilitate outplacement of long-term older State hospital patients and reduce the stays of those newly admitted (Powers, 2002).

The Bureau of Geriatric Psychiatry coordinates with community mental health centers and Area Agencies on Aging statewide, providing training and consultation to them, and to nursing homes, assisted living facilities, and protective services caseworkers. The Bureau spearheaded a coalition for geriatric mental health in Alabama.

Recently, the Department of Mental Health and Mental Retardation collaborated with the Alabama Department of Senior Services to create and expand community care waiver slots for persons with dementia or serious mental illness. The specialized hospital assesses individuals, documents deficits and needs, and works closely with family caregivers and with supportive housing providers in the community. The result has been dramatically reduced lengths of stay, recidivism, and institutionalization of older adults.

## **The National Coalition on Mental Health and Aging**

The National Coalition on Mental Health and Aging was founded in 1991 and serves as a forum for more than 60 Federal agencies and national organizations to gather to discuss mental health and aging issues. The Coalition provides opportunities for advocates, professionals, and government policymakers to develop collaborative working relationships and to educate one another in a nonadversarial setting. Each member agency has resources that may be relevant to the housing and

service needs of older adults with serious mental illnesses.

One of the most important activities of the National Coalition on Mental Health and Aging has been to work toward agreement on a national agenda of goals to improve the welfare of older people with mental health needs. A 1999 national conference and follow-up work led to creation of the set of recommendations that follows:

- The Medicare law needs to be amended to provide parity coverage for mental health care and to include coverage of prescription drugs. (While recent legislation addresses prescription drug coverage, the lack of parity remains.)
- A consistent national policy for Medicare coverage of mental health services needs to be established.
- The Medicaid Institutions for Mental Diseases exclusion should be eliminated to encourage the development of community-based services by removing the barriers restricting the development of Home and Community-Based Waivers.
- The institutional bias in Medicare and Medicaid versus community-based alternatives must be eliminated.
- Federal agencies under the Department of Health and Human Services should increase staff expertise on aging, mental health, and substance abuse.
- The effort to build coalitions at the State and local levels involving aging, mental health, substance abuse, and primary health care should be continued, expanded, and supported.
- The older adult mental health consumer self-advocacy movement should be nurtured and supported.
- Research should address new treatments and provide scientific information to battle the still pervasive stigma regarding mental illness in

older adults.

Further information on the National Coalition on Mental Health and Aging is available at [www.ncmha.org](http://www.ncmha.org).

## State Mental Health and Aging Coalitions

At about the same time that the National Coalition was being initiated, the first statewide mental health and aging coalition began in Oklahoma. The success of the national and Oklahoma coalitions encouraged the development of coalitions in other parts of the country.

Since the mid-1990s, the Federal Substance Abuse and Mental Health Services Administration (SAMHSA) has supported the development of State coalitions with grants to AARP and to the National Association of State Mental Health Program Directors. These grants have supported initiatives to identify, design, and train networks of older adults, mental health services providers, and advocates to build mental health and aging coalitions at the State and local level (U.S. Administration on Aging, 2001). The goal of these coalitions is to increase public awareness of mental health and aging issues and to improve mental health service provision to older adults.

SAMHSA funded a similar project with a grant to AARP to support the development of both State and local coalitions that include the primary care and substance abuse treatment systems in the coalition process. To date, approximately 35 State and 10 local coalitions on mental health and aging have been formed (U.S. Administration on Aging, 2001). SAMHSA also funded a project through the AARP Foundation to evaluate earlier coalition-building efforts and identify and disseminate successful practices. Efforts are currently underway to establish stronger linkages between the National Coalition on Mental Health and Aging and the State and local coalitions.

## Federal Initiatives

As part of the New Freedom Initiative, SAMHSA's National and Statewide Coalitions to

Promote Community-Based Care under Olmstead project, administered by the Center for Mental Health Services, has supported statewide groups focused on overcoming barriers to community integration for children, adults, and older adults with serious mental illnesses. The coalitions include policymakers, funders, providers, advocates, consumers, and family members.

One of the major accomplishments of the State Olmstead coalitions has been their work to define the range of community services, including nontraditional services (e.g., transportation, supported employment) that are required for individuals with mental illnesses to get out and stay out of institutions, and to ensure that the needs of individuals with mental illnesses are a priority in statewide Olmstead planning. In many States, this work has resulted in the recognition that the need for such services as housing, transportation, and employment support cuts across types of disability, age, and culture in determining an individual's ability to participate in community life.

In 2001, SAMHSA began development of a strategic plan on aging. This comprehensive, 5-year plan will serve as a road map for future initiatives and foster cooperation and collaboration among the aging, health, mental health, and substance abuse service systems. In 2002, CMHS established the Positive Aging Resource Center. In 2004, nine targeted capacity expansion grant sites were implementing evidence-based programs for older adults.

Also, as noted previously, in large part due to the involvement of vocal advocates, the President's New Freedom Commission on Mental Health cited the lack of services for older adults with serious mental illnesses as a significant service system gap. The Commission recommended that Federal agencies identify and consider payment for core components of "evidence-based collaborative care" delivered in primary care settings, including case management, disease management, supervision of case managers, and consultations to primary care providers by qualified mental health specialists that do not involve face-to-face contact with clients. (New Freedom Commission on Mental Health, 2003, p. 66)

## Conclusion

As the aging population in this country continues to increase, so, too, does the need to provide appropriate, accessible, community-based services to older adults with serious mental illnesses. These individuals, by virtue of their age, comorbid medical illnesses, poverty, and isolation, are vulnerable to being unnecessarily or prematurely institutionalized, or to being kept in institutions when their conditions do not warrant custodial care.

Numerous fiscal, service system, clinical, and societal barriers make it difficult for older adults with serious mental illnesses to access appropriate care in the community. Not the least of these is stigma, which attaches both to mental illnesses and to older adults. A chronically underfunded mental health system, fiscal disincentives in both Medicaid and Medicare, and a lack of community-based alternatives also place older adults at risk for out-of-home placement.

In spite of, or perhaps because of, these barriers, communities around the country have developed innovative prevention and treatment interventions that address the multiple and complex needs of older adults with serious mental illnesses. A major focus of these interventions is coordination of all the programs and services that older adults require. Because many

older adults have comorbid medical conditions and they prefer to receive their treatment in primary care settings, the integration of mental health treatment into primary care settings receives special emphasis.

The vision of the Substance Abuse and Mental Health Services Administration, which oversees Olmstead planning for people with serious mental illnesses, is “a life in the community for everyone.” This goal closely mirrors the vision articulated in the Final Report of the President’s New Freedom Commission on Mental Health, which emphasizes that all people with mental illnesses should have access to effective treatment and supports to enable them to live, work, learn, and participate fully in their communities.

Though progress has been made in the care of older adults with serious mental illnesses, much remains to be done to achieve the fundamental systems transformation envisioned by the New Freedom Commission and to support full community integration. In the past, communities may have wanted to further integrate older adults with mental illnesses into community life. Today, the *Olmstead* decision and the New Freedom Commission provide specific guidance for accomplishing this goal.

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