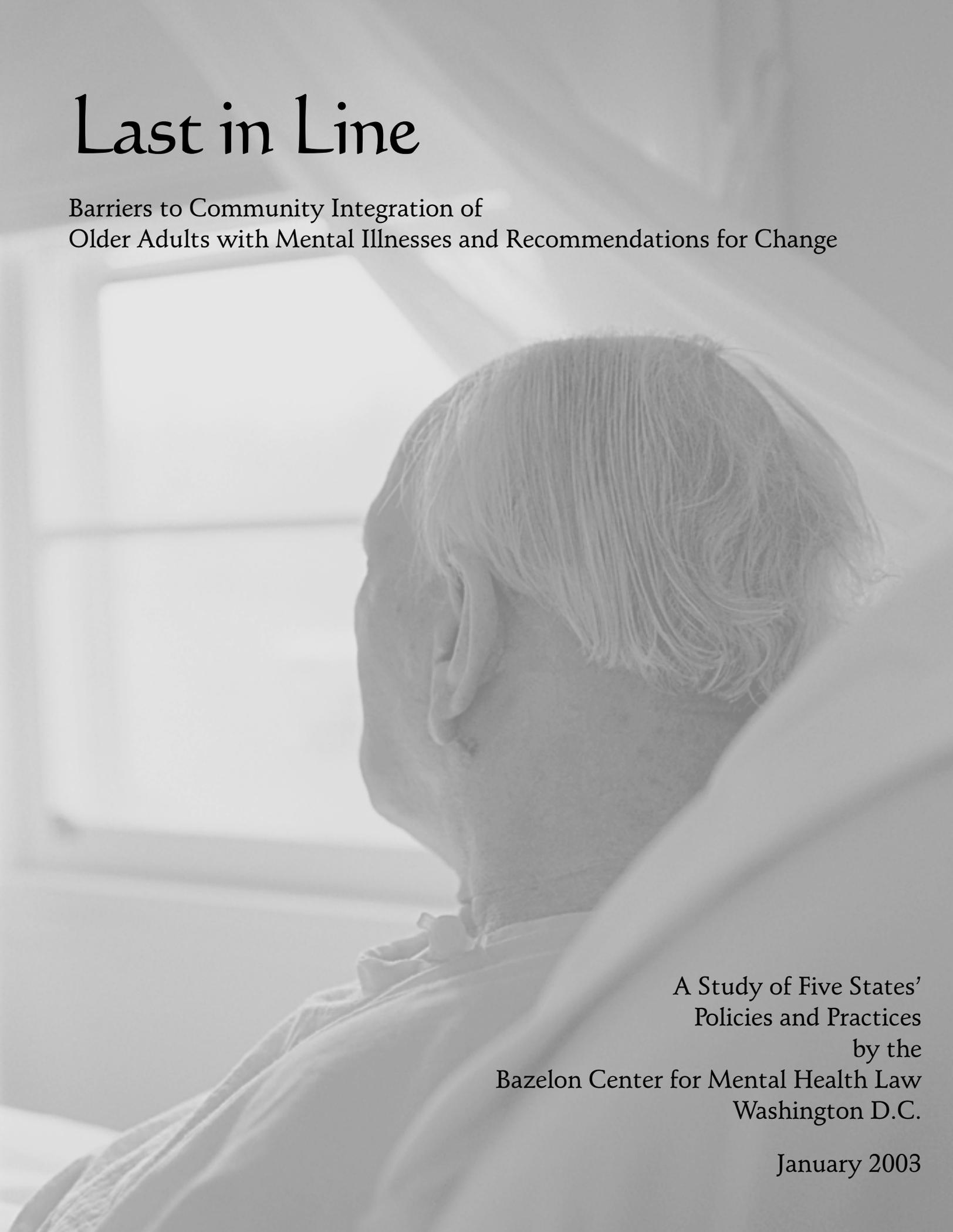


Last in Line



Barriers to Community Integration of
Older Adults with Mental Illnesses and Recommendations for Change

A Study of Five States'
Policies and Practices
by the
Bazelon Center for Mental Health Law
Washington D.C.

January 2003

© Copyright January 2003 Judge David L. Bazelon Center for Mental Health Law, Washington D.C. This report was prepared by staff attorney Jennifer Mathis and Robert Bernstein, executive director of the Bazelon Center, and was edited and designed by communications director Lee Carty. Photo by Human Issues Collaborative.

The Bazelon Center is a national nonprofit organization founded in 1972 by lawyers and mental health professionals. Today it is the leading legal advocate for people with mental disabilities, with the mission of protecting and advancing rights of adults, older adults and children with mental disorder to exercise meaningful life choices and to enjoy the social, recreational, educational, economic, political and cultural benefits of community living. Using a coordinated approach of litigation, policy analysis, coalition-building, public information and technical support for local advocates, we work to end their segregation, incarceration and marginalization and the disintegration of their family structure, and to assure them access to needed services and support. We are deeply grateful to the Retirement Research Foundation for making possible the research for and development of this report and to the John D. and Catherine T. MacArthur Foundation for its support for the Bazelon Center's general program.

The executive summary is online at www.bazelon.org. An addendum to this report more fully describes, state by state, our findings in the five states studied and includes recommendations specific to each state. It is available separately. To purchase the report, go to the online bookstore on that site or send check or credit card authorization for \$6.50 (or \$9.50 with the addendum) plus \$4 for postage and handling to the address below. For the addendum only, send \$3 plus \$2 for postage and handling. Bulk discounts for 10 or more to the same address are available by request. There is an additional administrative charge of \$4.50 per order for billing.

Publications Desk
BAZELON CENTER FOR MENTAL HEALTH LAW
1101 15th Street NW, Suite 1212
Washington D.C. 20005-5002
www.bazelon.org
202-467-5730; fax 202-223-0409; TDD 202-467-4232
pubs@bazelon.org

Contents

Executive Summary	v
Introduction	1
The Olmstead Planning Process	2
Older Adults Are Underserved in the Community Mental Health System	2
Geriatric Mental Health Experts Are Missing from Olmstead Planning	4
Barriers to Community Integration	7
Stigma	7
Lack of Knowledge	8
Lack of Coordination	8
Inadequacy of Medicaid and Medicare	10
Logistical Barriers Such as Lack of Transportation and In-Home Services	13
Lack of Housing	13
Insufficient Outreach	14
Inadequacy of Managed Care Coverage	15
Public Funding of Institutional Care	15
Lack of Political Will	16
Limits of Nursing Home Screening	17
Exclusion of Dementia from State Mental Health Programs	18
Bureaucratic Stumbling Blocks	18
Delays in Olmstead Planning	19
General Recommendations	21
Conclusion	23
Notes	24

Last in Line

Barriers to Community Integration of Older Adults with Mental Illnesses and Recommendations for Change

Older adults with mental illnesses remain segregated in nursing homes and other isolating environments, even as other groups have begun to gain full membership in the community. The Bazelon Center for Mental Health Law, with support by the Retirement Research Foundation, undertook a project to analyze the barriers that have led to the neglect of older adults in states' efforts to shift mental health services to the community. The Center has conducted extensive work on issues related to community integration for individuals with mental disabilities generally, most recently in the context of the Supreme Court's 1999 decision in *Olmstead v. L.C.*¹ While in most states *Olmstead* has not yet produced tremendous progress, we hoped to discover whether the unique needs of older adults with mental illnesses pose particular challenges to creating community-based services for this population, and to what extent states have been addressing those challenges in their planning for community integration.

While it was not possible to study all 50 states in depth, we chose to focus on five: Pennsylvania, Alabama, Illinois, Michigan and Nevada. We chose these because of the variety they offer in geographic location, population age, mental health and aging infrastructure, and *Olmstead* planning efforts. The goal was twofold: 1) to identify the state policies and practices that create barriers to community integration for older adults with mental illnesses and the efforts that have been successful in overcoming some of these barriers, and 2) to formulate recommendations for change to reduce the number of older adults with mental illnesses needlessly segregated in institutions of various types and facilitate better (and, often, less costly) service models in community-integrating settings.

We began with a survey questionnaire sent to mental health and aging advocates, service providers, government officials and consumers to determine what

steps their states were taking to facilitate community integration of individuals with disabilities, how they were addressing particular issues that affect older adults with mental illnesses, what factors they saw as the primary barriers to community integration for this population, and what the state was doing to address those barriers. We then conducted follow-up interviews with survey respondents and many other individuals to whom we were directed as we proceeded. We visited four Michigan, Illinois, Pennsylvania and Alabama to meet with interviewees and observe settings for older adults with mental illnesses. We also reviewed documents provided by interviewees, including long-term care studies, legislative bills, testimony and geriatric mental health training materials and manuals. Our final report focuses more on information from interviews than from the survey, as the interviews yielded more detailed and comprehensive information.

The Bazelon Center hopes to build on this project with state-based efforts to promote community integration of older adults with mental illnesses. With the relationships we developed through this project and the knowledge we gained about specific policies and practices that hinder access to community-based mental health services for older adults, we hope to work with organizations in the states studied—or other states—on strategies to modify some of these policies and practices and eliminate barriers.

The project yielded many significant findings, described in detail in the full report and a state-by-state addendum. We found that the overarching barriers to community integration across all of the states we studied were consistent with barriers noted in several recent national studies, such as the Surgeon General's 1999 report,² an Administration on Aging report the same year,³ and a 2002 report by the Substance Abuse and Mental Health Services Administration.⁴ The principal barriers we found across all five states were:

- stigma among older adults about the receipt of mental health services;
- lack of knowledge about geriatric mental health issues on the part of primary care physicians, mental health providers and senior service providers;
- lack of coordination between aging and mental health agencies;
- unavailability of transportation to assist seniors in accessing services;
- unavailability of in-home mental health services;
- inadequacy of Medicaid and Medicare reimbursement schemes to finance community-based mental health services for older adults;
- lack of housing;
- inadequacy of managed care coverage;
- the bias of public funding schemes favoring institutional care;
- lack of political will for reform;
- the limits of screening to prevent unnecessary confinement of individuals with mental illness in nursing homes;
- bureaucratic stumbling-blocks;
- the exclusion of dementia from many state community mental health programs; and
- delays in states' *Olmstead* planning for community integration.

We also found policies and practices particular to one or more of the states that have the effect of hindering development of community-based services for older adults with mental illnesses. For example, the mental health department in Pennsylvania excludes older adults with mental illnesses in a “psychiatric transitional facility” from discharge to the state’s community-based mental health programs; Alabama does not permit Medicaid reimbursement for case management services provided by both mental health and senior service providers, even though those case management services secure very different types of services—all of them important to older adults with mental illnesses; Illinois has directed an enormous percentage of its long-term care resources to nursing facilities rather than community-based services and funds services for a large number of individuals in “institutions for mental diseases” that provide few services to residents and generate little federal reimbursement; Michigan’s state Medicaid program has implemented a policy that would convert the bulk of the state’s community-based mental health

services funded by Medicaid into discretionary services; and Nevada has only one outreach program targeting older adults with mental illnesses in the entire state.

In an addendum to the main report describing our findings in each of the states, we make recommendations for modifying some of these state policies and practices as part of efforts to promote community integration and in hopes of spurring critical evaluations in all states about the biases against community integration for older adults with mental illnesses that are embedded in policies and practices guiding public healthcare and reimbursement systems. The report concludes with a set of general recommendations for:

- Outreach programs that target older adults with mental health needs.
- Coordination between mental health and aging systems.
- A public funding stream to assure that older adults with mental illness are able to be served in the community and not be forced to enter a nursing facility for lack of affordable community options.
- Training of primary care physicians in geriatric mental health issues.
- Cross-training of mental health and aging services agencies and providers.
- A centralized source of information on substantive geriatric mental health issues and updated information about available resources in each area.
- Inclusion of dementia in mental health programs.
- Redirection of funds from closure and consolidation of state hospitals.

Older adults with mental illnesses should not be pushed to the end of the line for access to the community integration that is their fundamental right.

1. *Olmstead v. L.C.*, 527 U.S. 581 (1999), holding that unnecessarily institutionalizing individuals with disabilities is a form of discrimination that may violate the Americans with Disabilities Act.

2. *Mental Health: A Report of the Surgeon General*, Chapter Five (1999), at <http://www.surgeongeneral.gov/library/mentalhealth>.

3. See <http://www.aoa.gov/mh/report2001>.

4. U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, *Promoting Older Adult Health: Aging Network Partnerships to Address Medication, Alcohol, and Mental Health Problems* (2002), http://www.ncoa.org/mem/promot_hlth.pdf.

Last in Line

Barriers to Community Integration of Older Adults with Mental Illnesses and Recommendations for Change

INTRODUCTION

Why are so many older adults with mental disorders consigned to segregated and isolating environments to receive the care they need? Why do so few receive the mental health services to which they are entitled in the community? In 2002 The Bazelon Center for Mental Health Law, with support by the Retirement Research Foundation, undertook a project to explore these questions because they have received so little attention in states' efforts to promote the community integration of people with disabilities required by the U.S. Supreme Court's *Olmstead* ruling.¹ To evaluate how states are fulfilling their obligations under the Americans with Disabilities Act (ADA) to address the rights of older citizens who have mental illnesses, identify the barriers that prevent older adults from receiving community-based mental health services, and recommend steps to eliminate some of those barriers, Bazelon Center staff surveyed and interviewed state officials, mental health and aging advocates, providers and consumers of mental health and aging services, operators of specialty mental health programs for older adults, academics, consultants and others.²

We focused on five states with varying demographic characteristics: Pennsylvania, Illinois, Alabama, Michigan and Nevada. Some longstanding obstacles were common to all five. These include older adults' reluctance to seek mental health services as traditionally configured, their inability to obtain transportation to service sites, their isolation

from linkages to community networks, the general lack of knowledge among primary care providers and mental health providers about how mental health issues present in older adults, and policymakers' continuing lack of political will to support community programs for older adults with mental health needs. We also found policies and practices particular to individual

states and tried to discern how these have operated to prevent the development of community-based mental health services for older adults, either by themselves or in conjunction with the common barriers. These states differ in their geographic and economic dimensions, and some have large older populations and some have traditions of progressive aging programs. Taken together, they offer a snapshot of how older adults with mental disabilities are faring in terms of accessing the services and supports that allow them to participate in their communities. Unfortunately, we found that, notwithstanding the rights of these citizens under the ADA and its "integration mandate," older adults with mental disabilities continue to encounter barriers that effectively exclude them from the mainstream.

Recently, several national reports have addressed the topic of older adult mental health services. The Surgeon General's 1999 Report on Mental Health devoted a chapter to mental health issues that arise among this population, the ways mental health services are delivered to older adults and some of the general barriers that make it difficult for them to access

Notwithstanding the rights of these citizens under the ADA and its "integration mandate," older adults with mental disabilities continue to encounter barriers that effectively exclude them from the mainstream.

community-based mental health services.³ In 2001, the federal Administration on Aging issued a companion document to the Surgeon General's report devoted exclusively to the mental health needs of older adults.⁴ Rather than focusing on the nature, diagnosis and treatment of mental health problems, as does the Surgeon General's report, the Administration on Aging report discusses the types of community-based services that could be used by older adults with mental health needs and some of the funding streams that can support those services. In April 2002, the Substance Abuse and Mental Health Services Administration and the National Council on the Aging released a publication that discusses successful models of aging-network partnerships with mental health, substance abuse and other service systems that have improved the provision of mental health and substance abuse services to older adults.⁵

This report by the Bazelon Center has two purposes: 1) to highlight the policies and practices we found that have the effect of barring access by older adults to community-based mental health services, and 2) to suggest changes that could reduce the number of older adults with mental illnesses served in segregating institutions of various types and facilitate better (and, often, less costly) service models in community-integrating settings. We hope all states will give serious consideration to these suggestions in their planning to expand access to community-based services by people with disabilities.

The *Olmstead* Planning Process

In 1999, the Supreme Court recognized in its *Olmstead* decision that unnecessarily institutionalizing individuals with disabilities is a form of discrimination that may violate the Americans with Disabilities Act. Every state has for many years administered services in segregated settings, such as state hospitals, nursing facilities and state centers for people with developmental disabilities. The *Olmstead* decision simply affirmed the integration mandate that had already been in federal regulations for almost a decade and was being largely ignored with regard to older adults who have mental illnesses. In the three years since the *Olmstead* decision, most states have begun some kind of planning process to facilitate the transfer

of people with disabilities from these institutional settings to community-based services.

This planning has moved very slowly, however. As of this writing, few states have issued plans⁶ and many of those that have been prepared lack the specificity and budgetary allocations necessary to assure their implementation.⁷ In its most recent report on *Olmstead* implementation, the National Conference of State Legislatures reported that only three state legislatures had implemented some of the *Olmstead* plan recommendations in 2001, and even in those states, most of the *Olmstead* plan strategies had not yet been implemented.⁸ Now state budget shortfalls and declining state revenues are expected to further delay *Olmstead* implementation.⁹

As a result, in most of the country the *Olmstead* decision has not produced a great expansion of community-based mental health services. While people with mental illnesses are less likely now than they were a decade ago to languish for years in state hospitals, many more are finding themselves on the streets, in jails and prisons, in nursing homes and in privately run board-and-care or "adult" homes that are often ill-equipped to meet their mental health needs.

Most striking, however, about the slow progress in developing community mental health infrastructure is the lack of attention to the needs of one of the most historically underserved populations—older adults with mental illnesses. This is particularly troubling in light of the near-absence of existing infrastructure to serve this group effectively in the community.

Older Adults Are Underserved in the Community Mental Health System

The Surgeon General's Report on Mental Health estimated that almost 20% of individuals 55 and older experience mental disorders that are not part of normal aging.¹⁰ The rate of suicide in the U.S. is higher among older adults than any other segment of the population.¹¹ While some older adults have lived with mental illnesses for years, many others develop mental disorders later in life—for example, depression, adjustment disorder or anxiety, which can result from the losses that often come with aging, such as loss of physical capacities, loss of social status and self-esteem and death of friends and loved ones.¹²

Yet pathetically few older adults are served by the community-based programs of state mental health departments. Most states have, at best, a patchwork of small projects to address the needs of older adults with mental illnesses in the community. According to the Surgeon General's Report on Mental Health, the "advantages of a decisive shift away from mental hospitals and nursing homes to treatment in community-based settings today are in jeopardy of being undermined by fragmentation and insufficient availability of such services."¹³ The federal Administration on Aging reports that individuals 65 and older, who constitute 13% of the national population, represent only 6% of the population receiving community-based mental health services nationwide.¹⁴ The data gathered in the states we studied confirm this deficit in services:

- In Illinois, where people 65 and older are 12.1% of the population,¹⁵ individuals in this age group represent only 2% of the population receiving community-based services funded by the Office of Mental Health in 2001-2002.¹⁶
- In Pennsylvania, where adults 65 and older constitute 15.6% of the state population,¹⁷ state data show that they received 4.7% of the community-based mental health services provided by the counties in FY 1998/99, 4.4% of Medicaid fee-for-service community-based mental health services in FY 2000/01, and 2.3% of Medicaid managed care community-based mental health services in FY 2000/01.¹⁸
- In Alabama, older adults constituted 8.6% of the population served by community mental health centers in FY 2001, and 13% of the general population.¹⁹

According to the Administration on Aging, only half of the older adults who acknowledge mental health problems receive treatment from either mental health professionals or primary care physicians, and only 3% report seeing a mental health professional for treatment.²⁰ Among older adults who do receive mental health services, many are not receiving other types of services that are necessary for them to remain in community settings. The Administration on Aging

report cites a study in which 40% of community mental health providers identified basic services such as transportation and home-help services as unmet needs for older adult clients.²¹

Many of the reasons for such neglect of older adults by the mental health system are long-recognized. For example, because they grew up during times when extremely poor treatment of and negative attitudes toward people with mental illnesses prevailed, the stigma surrounding mental health treatment disproportionately affects older Americans and consequently they tend not to seek mental health services as traditionally configured.²² Denial of mental health problems is also common among older adults, who often resist seeking mental health services for fear of losing control over their lives.²³ Other problems include barriers to access such as lack of transportation, the cost of medical treatment and prescription drugs, the unavailability of mental health services in rural areas, the physical inability to come to an office to receive services and the isolation of older adults in general.²⁴ Finally, as exemplified by the horrible geriatric back wards formerly ubiquitous in state psychiatric hospitals, the mental health service system has a tradition of viewing older adults as a drain on resources, unworthy of much beyond custodial care.

Public funding of both mental health services and aging services is generally inadequate to meet existing needs, and segregation of funding streams results in fragmentation of services.²⁵ Even individuals who are Medicaid-eligible have difficulty obtaining sufficient services, as most state Medicaid plans severely limit coverage of community-based mental health services, personal care services and home health services.

Many states have Medicaid home- and community-based services waivers, which enable them to waive certain Medicaid requirements and provide services in community settings to a limited number of Medicaid recipients who would otherwise be served in a nursing facility, hospital or institution for individuals with developmental disabilities.²⁶ Such waivers can be

As exemplified by the horrible geriatric back wards formerly ubiquitous in state psychiatric hospitals, the mental health service system has a tradition of viewing older adults as a drain on resources, unworthy of much beyond custodial care.

specifically targeted to serve older adults who need nursing care or care provided in a psychiatric hospital. Yet no state, as far as we know, has specifically targeted a waiver to serve older adults with mental illnesses. Some have targeted nursing-facility waivers to serve older adults, but those waivers focus primarily on nursing needs rather than mental health needs.

While Medicaid typically cannot be used to address all the needs of older adults with mental illness in the community, states are required to cover nursing home services under Medicaid. As a result, Medicaid funding schemes create an incentive to place older adults with mental illnesses in nursing homes, where reimbursement for their care is readily available.

A number of other factors make it harder for older adults to receive mental health services. These include the lack of coordination and collaboration between the mental health and aging systems, gaps in services provided by each system, the shortage of individuals trained in geriatric mental health (psychiatrists, psychologists, social workers, home health workers, nurses and primary care physicians) and the lack of organized support and advocacy groups among older adults with mental illnesses.²⁷

Lack of expertise in geriatric mental health issues among primary care providers, mental health professionals and aging-service professionals is a significant problem. Many older adults cannot live successfully in community settings only because mental disorders are not properly recognized, diagnosed and treated in age-appropriate ways. For example, primary care physicians have extremely low rates of recognition and identification of mental disorders in older adults²⁸ and older adults are more likely to report somatic symptoms than psychological ones.²⁹ It is often harder for untrained professionals to identify mental illnesses in older adults because they have a different clinical presentation than younger people;³⁰ high comorbidity with other medical disorders also makes assessment and diagnosis harder in older adults, as symptoms of somatic disorders may mimic or mask signs of a mental illness.³¹ Furthermore, antipsychotic medications have an increased risk of damaging side effects, such as tardive dyskinesia, in older adults.³² Notably, mental health counseling and support interventions have been shown to result in substantial delays in nursing home admission for older adults.³³ These services, however, are scarce.

Geriatric Mental Health Experts Are Missing from *Olmstead* Planning

In light of the significant national attention given to mental health and aging issues during the past couple of years, including recognition of the barriers listed above, it is puzzling that efforts to address these issues have been absent in *Olmstead* planning. A likely explanation is that people with experience in addressing the unique needs of elders with mental illnesses are seldom involved in the *Olmstead* planning process. Most of the individuals we interviewed who had expertise in older adult mental health issues had not participated in *Olmstead* planning processes. Advocates, providers and consumers of mental health services and a parallel set of stakeholders representing aging services have been involved, but they represent relatively isolated systems and do not bring to the table the combined perspective and experience of those who deal with older adult mental health issues.

Our visits and interviews for this project revealed that few people involved with the mental health system have had experience with the particular problems faced by older adults accessing mental health services, and few individuals involved with the aging system have experience with the problems faced by older adults with mental illnesses. Given the above-noted barrier, this is no surprise.

Most of the mental health advocates we interviewed (varying by state, but including stakeholders such as long-term care ombudsmen, protection and advocacy attorneys and members of state chapters of mental health advocacy groups) had not had occasion to focus on older-adult access issues. Despite the substantial numbers of older adults in their states who have mental illnesses and their history of segregation and neglect by public systems, many advocates were unaware that older adults with mental illnesses have unique needs not being addressed by *Olmstead* planning efforts. These advocates reported receiving few calls about older adult issues. They tended to view the barriers to serving older adults in the community as the same barriers that keep people of any age from obtaining community-based mental health services.

Many community mental health providers had not taken the initiative of establishing appropriate partnerships with senior service systems to conduct effective

outreach to elders with mental illnesses and to provide mental health services in settings that are not threatening to seniors or associated with stigma.

Similarly, aging-system workers tended to have relatively little experience with clients who have significant mental health needs. Most of the programs supported by aging departments and area agencies on aging—primarily services funded by Title III of the Older Americans Act, such as home-delivered meals, housekeeping services and case management, and Medicaid-funded nursing-facility waivers that provide home- and community-based services to individuals who require the level of care provided in a nursing facility—are geared toward assistance with medical problems.

In many respects, mental health issues (and especially serious mental illnesses) are considered by the aging-services system to be ancillary matters that are the responsibility of other agencies. On the other hand, many aging advocates have a great deal of experience with individuals who have dementia. To an extent, this is by default, since mental health departments often do not provide services for people with dementia, justifying this by considering dementia a “cognitive impairment” and not a “mental illness.” Based on this array of factors, aging advocates have tended to view the barriers to serving older adults in the community primarily in terms of the difficulty of securing community-based nursing-facility waiver slots and services to respond to medical needs.

While aging-system workers generally refer individuals with known or obvious mental health impairments to the mental health system, there is seldom any mechanism to ensure recognition and assessment of less obvious mental health issues in older adults. Most important, there is seldom any mechanism for bringing mental health workers into senior centers, individuals’ homes, senior public housing and other settings where older adults may be assessed without having to go to a mental health clinic or follow up themselves on a referral. As confirmed by virtually every geriatric mental health specialist we interviewed, it is extraordinarily

difficult to get older adults to seek out mental health services themselves. And even if they do seek services in community mental health programs, they are likely to find themselves assigned low priority and offered little beyond medications.

The lack of coordination between the aging and mental health systems was strikingly reflected in the responses to a written survey we sent out as part of this project. We received many responses from mental health advocates and providers, area agencies on aging, senior services providers and others stating that they were *unable* to answer questions about community-integration planning for older adults with mental illnesses because they were not involved with such efforts. Follow-up interviews with many respondents revealed that they did have some role in community-integration planning, but did not focus on the needs of older adults with mental illnesses. Respective mental health and aging advocates were frequently unaware of the existence of, or work done by, coalitions involved in efforts to improve mental health care for older adults.

A great many of the individuals interviewed, including some state officials, noted that many older adults with mental disabilities are being served in nursing facilities, psychiatric hospitals and other institutional settings only for lack of basic services in the community. Many of them could be served in more integrated settings, but are institutionalized because, among other things, public

funding is more readily available to support services in the institutional settings. Yet older adults and family caregivers generally prefer community-based services, and providing these services has significant potential to reduce costs.³⁴ Accordingly, it would make sense to address some of the barriers to providing community-based services for this population as part of *Olmstead* planning or as part of a discrete effort to reduce unnecessary institutionalization.

States’ awareness of the problem predates the *Olmstead* decision. For example, in 1997, Illinois’ legislatively mandated Advisory Committee on Geriat-

Most community mental health providers had not taken the initiative of establishing appropriate partnerships with senior service systems to conduct effective outreach to elders with mental illnesses.

ric Services prepared a report discussing the barriers to older adults' access to mental health services and making recommendations to address those barriers.³⁵ The committee's study documented a tremendous unmet need for older adult mental health services. Seventy-two percent of the respondents to a survey of mental health agencies and 51% of the respondents to a survey of senior services agencies reported that they encounter elderly individuals requiring mental health services on a daily or weekly basis.³⁶ Respondents reported significant

States' awareness of the problem predates the *Olmstead* decision

barriers in serving this population, with the top reasons being refusal of services, unavailability of services, waiting lists for services and lack of transportation.³⁷

We hope the *Olmstead* requirements to develop and implement a plan to reduce unnecessary institutionalization will provide the impetus for all states to demolish the barriers that are keeping older adults with mental illnesses at the end of the line for access to community-based services.

BARRIERS TO COMMUNITY INTEGRATION

The summary that follows is based on our written survey, a review of various reports and state policies, interviews with numerous stakeholders and site visits. The appendix includes more detailed state-by-state reviews of the significant factors affecting achievement of the aims of the integration mandate for older adults with mental illnesses, including dementia. Our recommendations—both within these reviews and in the next section—are not prescriptions for how individual states ought to proceed with regard to identified issues, but rather an indication of the kind of ongoing deliberations we had hoped to see (but generally did not) as states grapple with reforms to promote community living for older adults with mental disabilities. Our hope is that these examples will spur just such deliberations, not only in the five states we reviewed but throughout the country, as advocates and other concerned stakeholders examine the structural factors in their states' service and reimbursement systems that work against the goal of community integration.

Much of the information from interviews and survey responses across all five states studied was consistent with the findings of the federal reports referenced above. The issues common to every state were:

- stigma;
- lack of knowledge;
- lack of coordination between mental health and aging systems;
- lack of transportation and in-home services;
- inadequacy of Medicaid and Medicare;
- lack of housing;
- lack of outreach to older adults;
- inadequacy of managed care coverage;
- bias of public funding schemes toward institutional care;
- lack of political will to change;
- limits on nursing-home screening;
- exclusion of dementia from state mental health programs;
- bureaucratic stumbling blocks; and
- delays in *Olmstead* planning.

Responses to our written questionnaire suggest that institutionalized older adults with mental illnesses receive low priority in integration planning.³⁸ Fully 100% of the respondents who ranked groups in order of priority listed either individuals in nursing facilities or individuals 65 and older in psychiatric hospitals as least likely to receive attention in integration efforts.³⁹ All of the responses that listed individuals in nursing facilities with the lowest priority listed people 65 and over in psychiatric hospitals with the second lowest priority.

Survey recipients were asked to rank the barriers to community integration of older adults in order of significance. The four barriers identified as most significant were lack of funding (listed as one of the top three by 100% of respondents), lack of political will, lack of affordable housing and lack of a trained workforce.⁴⁰ The surveys also suggested that states have not made much effort to explore funding initiatives or policy changes for expanding community-based services for older adults with mental illnesses.

The interviews we conducted with stakeholders yielded particularly useful information to clarify what the surveys revealed. In addition to common barriers, we found specific policies and practices that have the effect of frustrating implementation of change consistent with the *Olmstead* decision and preventing older adults' access to community-based mental health services. Some of these policies and practices may be unique to these states, while others are known to occur more widely. Taken as a whole, they paint a ground-level picture of a nationwide need to reverse the continued segregation of older adults with mental illnesses and their relegation to the margins of society.

Stigma

Interviewees in all states reported barriers created by stigma among older adults—and often their family members as well—emphasizing the need to offer mental health services in non-threatening ways and environments. Providers noted that referrals of individuals to their programs overwhelmingly come from sources other than the clients themselves. Most come

from other service agencies, from the individuals' primary care physicians, and from police.

A specialty provider of older adult mental health services in one of the states recalled a client whose wife turned and walked away any time he mentioned to others that he was participating in a mental health program. She noted that clients often use terms such as “crazies” and “nuthouse” to describe the program, but come anyway only because they have seen that the program’s benefits outweigh the negativity associated with it.

Lack of Knowledge

Another commonly cited barrier is lack of knowledge about geriatric mental health among primary care providers, nursing-facility staff and mental health professionals. For example, many of these individuals do not recognize depression in older adults, particularly because it may manifest itself in a way similar to dementia—a condition not treated by some of the states’ mental health programs. Advocates report that older adults are sometimes turned away by psychiatric emergency services simply because they are older. They are frequently seen as having dementia because of their age and too often a proper evaluation of their actual mental health needs is not done.

Many nursing facility staff also do not know how to spot depression in their residents, advocates note. They do not have time or experience to identify residents with mental health needs properly and frequently have no desire to do so. Doctors, too, often lack the expertise, time or desire to diagnose mental health issues in older adults. Sometimes this is due to ageism—a feeling that older adults are at the end of their lives and it is not worth the time to treat mental health issues. Many individuals cited as an underlying factor the lack medical-school training in geriatric mental health.

One of the poorest states in the country, Alabama has not been known for offering an especially rich package of publicly funded community mental health services. Yet the state has managed to serve a higher percentage of older adults than any of the other states we studied, and a higher percentage than the national average. Part of the reason may be the statewide

commitment to providing training in geriatric mental health issues to individuals in a variety of settings—community mental health providers, assisted-living providers, area agencies on aging, senior center staff, nursing home staff, family caregivers, students and others.⁴¹ While the availability of services is more limited than in many other states, the extensive train-the-trainer sessions have probably contributed to the fact that, relatively speaking, a surprisingly high percentage of older adults are receiving some community-based mental health services.

While the Alabama trainings reach a wide variety of individuals in the aging, mental health and nursing facility systems, the training program runs on a limited budget (though volunteer hours are used as well), and its impact on mental health and aging services is necessarily limited. One area agency-on-aging director noted that, although the agency had a dementia-education trainer on staff, most of the staff at the senior centers and staff who answer telephone calls do not have the knowledge to identify clients with potential mental health issues and do not know what resources exist. A legal advocate for elders noted that she would not have any idea what issues to consider in dealing with clients with mental illnesses, and suggested that a short guide laying out the main issues that arise for elders with mental health needs and listing existing resources would be helpful.

What was especially striking in our state visits was how little information about the particular barriers faced by older adults in need of mental health services has come to the attention of either mental health or senior advocates. Because these issues have been so infrequently discussed beyond a small subset of advocates and providers, knowledge of them has not filtered out to the advocates who play a crucial role in assisting individuals in obtaining mental health services and aging services.

Lack of Coordination

Individuals in all states described a lack of coordination between mental health and aging systems in addressing the needs of older adults. Many cited as part of the reason both types of agencies’ reluctance to take on the complexities of serving older adults with mental illnesses. The services provided by each set of

agencies are difficult to provide in isolation, without addressing the other needs of an older adult with a mental illness. Many mental health centers are reluctant to serve this population because of the practical difficulty of providing case management for older adults with complex—though common—medical issues, such as congestive heart failure or arthritis and understanding their unique mental health needs.

States have taken various steps to bring the two types of agencies together. In some Pennsylvania counties, teams composed of representatives from the area agency on aging and the county behavioral health office meet periodically to discuss policies and practices affecting services for older adults with mental illnesses, and staff from both agencies work together to assess individuals and coordinate services. Pennsylvania advocates, providers of geriatric mental health services and state officials agree, however, that the existing programs are nowhere near sufficient to address the needs of older adults with mental illnesses.

In parts of Illinois, area agencies on aging are quite successful in coordinating with mental health agencies to provide appropriate services for their clients. In other sections of the state, however—particularly rural areas—coordination is extremely poor. Some aging-services providers have had trouble persuading mental health providers even to come into their area. Often it is difficult to determine what services exist in the area, as many aging-services providers have no centralized list of resources.

Some of Alabama's area agencies on aging have recently begun to include mental health services in their nursing-facility waiver programs. Ironically, mental health center outreach teams have sometimes found themselves met at an individual's doorstep by a competing team from a senior services provider. While recognition of the need to integrate mental health and aging services is a positive development, it is unfortunate that in some areas multiple agencies compete to provide services while in others no one can provide needed services. Some mental health providers warn that senior services providers should not be in the business of offering their own mental health services instead of

reaching out to mental health centers to coordinate services. While these senior service agencies hire and bill Medicaid for psychiatric social workers and psychiatric nurses, they lack the structure to provide adequate consultation and supervision for their mental health workers, according to some.

Other than serving individuals in Medicaid waivers, however, most of Alabama's area agencies on aging have not focused on the mental health needs of older adults. Few senior programs are funded by Older Americans Act money specifically to address older adults' mental health needs. One area agency-on-aging director discussed a very successful adult day health program for individuals with Alzheimer's disease in Tuscaloosa—made possible by grant money and providing services on a sliding fee-scale basis—but noted that there was little else in the way of services geared toward older adults with mental disabilities.⁴²

Partnerships between mental health and aging agencies are difficult to develop without a sustained commitment to support them on at least a local government level.

Americans Act, Medicare and Medicaid state plan services make it difficult to avoid fragmentation. In Alabama, funding for specialty older adult mental health services comes primarily from community mental health centers. In Nevada, funds for the state's primary specialty program come from the Division of Aging. In these states, more collaboration between mental health and aging would doubtless facilitate better services and more effective use of resources. Nonetheless, we found examples of collaboration between mental health and aging systems, many of which have successfully used joint funding strategies.

Pennsylvania has used federal mental health block grant money to fund six pilot programs designed to provide outreach, assessment, service coordination and outcome monitoring for older adults. Additionally, various small specialty programs, primarily in the Philadelphia and Pittsburgh areas, provide an assort-

Partnerships between mental health and aging agencies are difficult to develop without a sustained commitment to support them on at least a local government level.

ment of community-based services: in-home evaluation and treatment; evaluation, individual, family and group therapy and other services based in senior centers; integrated programs where older adults receive mental health and medical care in the same place; mental health center-based geriatric services; and Medicare-funded partial hospitalization programs in senior centers. Most of these initiatives are financed by county-based mental health funding and funds from area agencies on aging.

Illinois has a number of specialty programs serving older adults with mental illnesses in select areas of the state. Most of these provide in-home services, mental health services in senior centers and other settings, and/or day treatment programs, and are supported by a combination of Medicaid funding, small grants from the Department of Aging, very limited Medicare reimbursement and, in some cases, private-foundation grants. Most of the specialty providers described a struggle for funding to maintain their programs from year to year.

Michigan has a few specialized community programs designed for older adults with mental illnesses, including small residential programs. Some provide mental health services to individuals in “homes for the aged,” which are licensed to serve older adults who do not need a nursing facility level of care. A few specialty programs have assertive community treatment teams for older adults, and some localities have mental health outreach programs as well. Some mental health agencies have aging specialists on staff. These specialty programs are funded primarily by Medicaid and Medicare dollars. One of the specialty program operators noted that the state mental health system has generally made efforts to reinforce collaboration between primary care physicians and mental health agencies.

Inadequacy of Medicaid and Medicare

While Medicaid and Medicare reimbursement may help pay for some of the services needed by older adults with mental illnesses, limited coverage under state Medicaid plans, state licensure requirements for Medicaid and Medicare providers, and the combination of different Medicaid rules often makes it difficult or impossible to use these programs as the primary funding streams for a specialty program.

Medicare, in addition to requiring a 50% contribution from clients for outpatient mental health services (as opposed to a 20% contribution for other services), requires that a program have a psychiatrist on staff. Furthermore, Medicare covers a very limited array of mental health services. Medicaid is a joint federal-state program and its rules differ from state to state. In some states, such as Pennsylvania, almost all of the specialty programs are funded by sources other than Medicaid and Medicare, relying instead on local dollars or area agency-on-aging funds.

Many older adults with mental illnesses are not eligible for Medicaid because the income-eligibility levels are so low in some states. Alabama, according to providers, has the most stringent eligibility standards in the nation. As a result, many indigent people do not qualify for Medicaid. Individuals whose income is slightly too high can receive only state- and local-funded services, which are sparse and generally inadequate to meet needs. Several informants reported that older adults who do not qualify for Medicaid are deterred from seeking community mental health services because they cannot afford the cost of an initial assessment, which runs approximately \$105. One community mental health center has suggested that centers unable to handle the needs of older adults contribute instead to a pooled fund that would enable the centers with geriatric programs to expand their capacity and serve other catchment areas.

A major barrier to developing community-based services for older adults with mental illnesses stems from restrictive licensure policies for Medicaid and Medicare providers. For example, Medicare will only pay for a licensed clinical social worker (LCSW) to provide social work services, although many specialty providers find it extremely difficult to budget for LCSWs to do work that is routinely done by other social workers. One specialty provider organization in Pennsylvania had hoped to become a Medicaid provider but was surprised to learn that it could not obtain Medicaid licensure because it would be required to have site-based mental health services and a psychiatrist on staff. The program, cited by SAMHSA as one of the successful models in the area of geriatric mental health, contracts with a geropsychiatrist rather than having a psychiatrist on staff in order to make the program economically feasible. Finally, Medicaid’s coverage of mental health

visits is more limited than what most of the program's clients require.

A problem noted by various specialty providers is the restrictiveness of Medicaid billing rules. For example, Illinois providers receive a daily reimbursement rate for psychosocial rehabilitation programs and cannot bill Medicaid for additional mental health services provided during the hours the program is supposed to operate. However, the five or six services billable under the psychosocial rehabilitation category (including assessment, treatment plan development, individual and group psychosocial rehabilitation services, and client-centered consultation) do not reflect the full array of services needed. Providers stress the tremendous importance of using case managers to assist older adults in these programs, but case management is not one of the reimbursable services in this category. Providers must either swallow its cost themselves or find other ways to provide it.

Illinois providers have had difficulty obtaining Medicaid reimbursement for assertive community treatment, one of the most important tools in serving older adults with mental illnesses if for no other reason than its outreach mode of service delivery. While assertive community treatment should be a voluntary, person-centered program, multiple outreach efforts are often necessary to engage a person in services. Unfortunately, this reality—and the incentive for providers to actively engage reluctant, at-risk individuals before involuntary hospital care may become necessary—is ignored by state policy that does not allow for billing of outreach visits when the individual refuses to see the worker.

Specialty providers in Illinois note the need for high-quality staff to address the complex needs of this population and the difficulty of keeping trained staff with the low reimbursement rates provided by Medicaid and Medicare. One provider noted that the amount Medicaid pays for a psychosocial rehabilitation program is approximately half of what is needed to operate her program. Another observed that Medicare assumes that a number of activities will be bundled into the services it reimburses, but the rates are insufficient to sustain that array of activities.

Another frustrating problem has arisen in Alabama as a result of competition to provide services. The Medicaid agency has refused to pay for case management services provided by both the area agency on aging and the community mental health center, on the ground that these services are duplicative, even though the services provided by each system are quite different. In the mental health system, case managers typically ensure that an individual is taken grocery shopping and to doctors' appointments, assisted with money management, and provided other related services. Case managers

One provider noted that the amount Medicaid pays for a psychosocial rehabilitation program is approximately half of what is needed to operate her program.

in the aging system ensure that an individual receives homemaker services, such as assistance with cleaning the house and light cooking. Upon being told by the Medicaid agency that case management services cannot be billed by more than one agency, community mental health center teams have withdrawn, leaving clients upset because case managers with whom they have developed a relationship are gone and they are no longer receiving needed services. The state Medicaid agency could reorganize billing codes to permit reimbursement for the different types of case management so that older

adults with mental illnesses can receive the full array of services to which they are entitled.

A recent decision by the Michigan Medicaid agency imposes a serious potential barrier to accessing community-based mental health services.⁴³ The decision states that the bulk of the community-based mental health services the state provides through its Medicaid managed care waiver—such as peer-directed services, family skills, housing assistance, extended observation beds, wraparound services—are not entitlements under the Medicaid program, but rather discretionary services that managed care entities are encouraged to provide out of cost-savings achieved with managed care. This decision seems to contradict basic Medicaid principles, which dictate that federal Medicaid reimbursement received by a state must be used to provide entitlement services. Yet the state is using federal Medicaid match money, which is included in capitated payments to managed care entities for Medicaid recipients, to fund services that may be provided or not, at the discretion of the man-

aged care entity. This policy, which is likely to be challenged, essentially converts much of Michigan’s community-based Medicaid mental health program into a block grant program and creates tremendous problems for enforcing the right to receive Medicaid mental health services.

The array of services provided under states’ Medicaid plans is typically inadequate to serve the mental and physical needs of older adults with mental illnesses who could live in the community. Many states have chosen to adopt Medicaid waivers allowing them to provide services to people who would otherwise be served in a nursing home setting. Because these nursing-facility waivers are designed to serve individuals who have nursing needs, they focus primarily on those needs and frequently provide little in the way of mental health services. Additionally, many states cap the permissible costs under their waivers at less than 100% of what it would cost to serve people in an institutional setting. These cost caps make it impossible for many waiver-eligible older adults to remain at home and receive the level of care they need.⁴⁴

Michigan’s nursing-facility waiver also has caps that are way below the cost of nursing home care and is geared primarily to serving those with physical disabilities. Waiver agents can, however, purchase mental health services for clients. Currently, the “MI Choice” waiver has been frozen at 11,000 individuals, although it was intended to serve 15,000, and no new admissions have been made. Waiting lists are not permitted. A pending lawsuit challenges the freezing of the waiver and the imposition of cost caps for participants. Increasing the cost caps for the waiver to 100% of the cost of nursing facility care and allocating funds to reopen admissions to the waiver would allow the state to serve older adults and individuals with disabilities more cost-effectively than in nursing facilities. Waiting lists should also be maintained to keep track of those who have sought but been unable to receive waiver slots. Waiting lists are crucial to an organized planning process to move people into community-based services.

The array of services provided under states’ Medicaid plans is typically inadequate to serve the mental and physical needs of older adults with mental illnesses who could live in the community.

Illinois also has a nursing-facility waiver for older adults, administered by the Department of Aging. It provides very limited services—up to four hours per day of personal assistance, meal preparation and adult day services. In contrast, the home-care waiver operated by the Office of Rehabilitative Services for individuals under 60 provides up to 24 hours per day of home-care services. Advocates note that the personal aides in the aging waiver are not trained to deal with individuals with mental illnesses. Moreover, most adult day services apparently will not take people with dementia. Advocates report that Illinois also licenses assisted-living

facilities, but these do not serve Medicaid clients, and in any event are generally not staffed adequately to address the needs of many individuals with mental illnesses. Expansion of the service hours in the aging waiver would likely enable the state to serve many individuals in less expensive home settings instead of in nursing facilities. The state might also consider creating a Medicaid nursing-facility waiver that is targeted to older adults with mental illnesses. This would create a single funding stream designed to ensure provision of the array of services required by Medicaid-eligible older adults with mental illnesses.

A major difficulty facing older adults who need mental health services in Pennsylvania is that, aside from a few small pilot projects and specialty programs, virtually no publicly funded community-based options are available for older adults with both medical and mental health needs. Medicaid covers only 15 half-hour visits by a home health aide each month. The options available to older adults, apart from their own homes, include personal-care homes and services in Pennsylvania’s home- and community-based Medicaid waivers for individuals who meet a nursing home level of care. Because the state prohibits individuals who require a nursing-home level of care from being served in personal-care homes, the only option for people who need nursing care is nursing-home placement, unless they are fortunate enough to obtain one of the limited slots in the Medicaid waivers. A pilot program eliminating the

prohibition on providing waiver services in personal-care homes currently serves 86 older adults with mental disorders, most of whom have a mental health diagnosis. The program has been able to provide integrated services to meet both the mental health and medical needs of individuals in personal-care home. Many other states permit waiver services to be provided in personal-care homes and assisted-living residences, and Pennsylvania could also pass legislation to do so.⁴⁵

Nevada has Medicaid home- and community-based waivers that serve people with physical disabilities and older adults and are primarily geared toward medical needs. According to the National Conference of State Legislatures, the state ranked 49th in home- and community-based waiver spending in FY 2001, with 75% of its Medicaid long-term care funds going to institutional care.⁴⁶

Other resources in the state are limited. Medicaid provides some funding for assertive community treatment teams, targeted case management and counseling. Case management services are covered only for a short period of time, however. The aging system funds some caregiver resource centers and Alzheimer's clinics. Assisted-living facilities are not publicly funded.

Another Nevada program provides assessment and service coordination on a short-term basis to older adults with mental illnesses—primarily depression. The program, which is attached to an inpatient geropsychiatric facility, began as a partial hospitalization program but no longer provides partial hospitalization due to Medicare restrictions. It is primarily financed by Medicare, which limits the types of services that can be provided. Medication, for example, is not covered unless the clients are also Medicaid recipients. The program includes a licensed clinical social worker, a part-time nurse and a psychiatrist. According to its staff, the program does not make any money and is fortunate when it breaks even. It survives only because the inpatient program attached to it generates sufficient revenue to support both programs, given the higher Medicare reimbursement rates for inpatient psychiatric services. Individuals with dementia are not served. Additionally, several very small programs funded by private foundations provide group counseling to seniors.

Logistical Barriers Such as Lack of Transportation and In-Home Services

A universal barrier is the unavailability of transportation for older adults to access mental health services, particularly in rural areas. A director of an area agency on aging in Alabama noted that her agency provided transportation for older adults to get to needed services, but said that service was limited for people located extremely far from services. Furthermore, some older adults are not able to leave their homes and many programs do not provide in-home mental health services.

Sometimes this is the result of state policy. For example, Pennsylvania has a Medicaid licensure rule that requires mental health providers to provide site-based services (i.e., within a clinic setting). A Pennsylvania program cited as a national model provides mental health services in individuals' homes and at senior centers, but does not provide site-based mental health services because it has found that most seniors are unlikely to come to a mental health center to receive services, especially physically frail elders, for whom such travel is difficult.

Nevada medication clinics may take between two and three months to schedule an appointment with clients. The state has very few mental health clinics—for example, the Reno area has only one. Rural areas have extremely little in the way of mental health services. To receive mental health services, clients must ordinarily come into the clinics, an obvious barrier for many older adults. The state has no mobile crisis unit and only very limited emergency mental health services.

Lack of Housing

The lack of affordable housing is a major barrier to obtaining community-based services for individuals with mental illnesses of every age in every state. As a rule, housing is not covered by public funding streams and payments for housing generally come from individuals' SSI checks or other sources. However, these dollars are usually insufficient. In Nevada, the cost of housing has increased sharply in recent years, but subsidized housing is scarce and waiting lists for Section 8 certificates are long.

Small increases in supplemental payments to SSI recipients to assist them in securing housing may bring cost savings to the state, as long as these payments are lower than the additional costs that the state would otherwise pay to house these individuals in institutions or nursing facilities.

Lack of housing is one of the reasons Illinois officials have been reluctant to move individuals out of institutions, even if mental health services are available in the community. The public housing authority in Chicago apparently has thousands of vacant units, but these are unavailable because of a large-scale renovation project. The state's largest mental health provider indicated, however, that while it would be difficult to find housing immediately for inappropriately institutionalized residents, over time the state could certainly find the necessary housing to place a large number of those individuals in community settings.

Insufficient Outreach

Outreach is critical to create for older adults entry points to mental health services. One effective approach is the “gatekeeper” model developed in Washington State, where community members such as meter readers, postal employees and store clerks are trained to identify and refer at-risk older adults who may need mental health services. This has proven an excellent way to reach elderly people living in their own or family members' homes, but it does little for residents of the congregate-living arrangements that house a large number of older adults with mental illnesses who have either remained undiagnosed or are not receiving adequate mental health care. Naturally, it also requires that services actually be available to the people identified.

Pennsylvania has funded six pilot programs based on the gatekeeper model. However, many people in Pennsylvania were placed in personal-care homes during the era when state hospital closures resulted in the “dumping” of patients into the community without appropriate planning for their needs. They are unnecessarily at risk of institutional placement as their mental health deteriorates. But because the state's Department of Aging does not send anyone into personal-care homes to assess residents' needs, the residents seldom have any way to connect to mental health services. Advocates

report that some personal-care home operators do arrange for appropriate mental health services for their residents, but many do not, and in some homes, residents' mental health needs are treated primarily through the use of medication. In any event, there is no effective mechanism for the aging or mental health systems to discover whether the mental health needs of personal-care home residents are being appropriately met.

While Alabama's Bureau of Geriatric Psychiatry trains mental health and aging workers to recognize mental health issues in older adults, the Bureau's program does not have an outreach component that targets older adults themselves. Accordingly, the programs do not reach isolated seniors who are not connected with senior services. Many mental health centers also do not target outreach to older adults, and serve them only when they actually contact the mental health center for services. As one mental health center director put it, these centers will provide help but “they aren't going to cross the street looking for” seniors to serve. The initial contact with community mental health centers is rarely made by older adults themselves, but is made overwhelmingly by primary care physicians and other agencies. Such a passive approach is not sufficient to address older adults' needs.

Funding is needed at the state or local level for more outreach programs to reach older adults with mental illnesses, including those in personal-care homes. Many current outreach efforts are targeted to individuals in senior centers but, as one state official noted, “only well elderly attend senior centers” and older adults with serious mental illnesses generally do not access services provided by area agencies on aging. Outreach efforts need to reach many more individuals.

Nevada has even fewer potential service system entry points for older adults with mental illnesses because the state has no network of local area agencies on aging. While very few providers serve this population, the state itself has created the Mental Health Outreach Program to serve individuals 60 and older who experience symptoms of mental illness. The program provides evaluation, counseling and case management primarily in individuals' homes but also in congregate-living facilities. The program was initially funded by Older Americans Act money through the Division on Aging. Recently, it received a supplemental grant from

the state tobacco settlement fund, part of which is earmarked to assist seniors in maintaining independence. The program relies on a team composed of an individual with a masters degree in gerontology, a licensed clinical social worker and a person with a masters in social work. Yet the outreach program is limited both in geographic scope and in services. According to program staff, it is the state's only outreach targeted toward older adults, and perhaps the only one targeted toward individuals with mental illness.

Inadequacy of Managed Care Coverage

While many had hoped that managed care would offer better coordination of services for individuals with complex needs, the overall experience with managed care coverage for older adults with mental illnesses has been problematic. Many people reported that HMOs have been very reluctant to cover innovative specialty programs for this population. In Pennsylvania, advocates and providers described how frequent failures of coordination in a Medicaid managed care program resulted in older adults' being shipped across town to a mental health clinic, only to find out that the geriatric specialist was not there at the time the person was sent.

In Michigan an advocate noted that the managed care system currently in place for Medicaid recipients with mental illnesses and developmental disabilities who receive community-based services creates a financial incentive for placement in nursing facilities. The managed care entities responsible for Medicaid clients receive a capitated rate for each client and must pay for community-based services that the individual is determined to need. If the individual needs nursing-facility services, however, then the managed care entity does not pay.

Public Funding of Institutional Care

Across all the states studied, sources noted that many older adults with mental illnesses are placed in nursing facilities only for lack of public funding for appropriate community-based options. The incentive to place people in nursing facilities is that Medicaid and Medicare will reimburse

for care provided in these facilities. In addition, Medicaid and Medicare are available to cover hospital care for older adults, including geriatric psychiatric care.

In response to a survey question asking whether states are redirecting funds previously invested in psychiatric hospitals or nursing facilities to community-based services for this population, or using Medicaid or other avenues to expand community-based services, the overwhelming majority of respondents either indicated that no such efforts were being made or left the question blank. Some mentioned cuts in Medicaid community services. Alabama state officials noted that redirection of funds to community services for individuals with mental illnesses was required by the settlement in *Wyatt v. Sawyer*, and indicated that Medicaid community-based services were being or had been expanded. A Nevada state employee referenced a pending legislative initiative to study long-term care needs and establish strategic plans for seniors and individuals with disabilities. In replying to a separate question, some survey responses noted expansion of Medicaid optional services in Michigan,⁴⁷ but also said that admissions to Michigan's nursing-facility waiver have been shut down.

Advocates and providers in Alabama note that, without a primary caregiver at home, few older adults are able to remain at home because publicly funded home health services would not be sufficient to support them there. Personal-care services are not part of Alabama's Medicaid plan. By contrast, Medicaid and Medicare funding is readily available for people placed in nursing facilities and for those 65 and older in psychiatric hospitals. Many advocates indicated that the politically powerful nursing home industry has made it extremely difficult to develop more community options because of concern about losing clients.

Pennsylvania, the state with the second-oldest population nationally,⁴⁸ devotes 90% of its spending on long-term care (itself two thirds of the state's Medicaid budget) to nursing-facility services.⁴⁹ Compared to the national average, Pennsylvania's taxpayers spend 40% more per capita on nursing-home services and 92.6% less per capita on home- and community-based services.⁵⁰ The reason is primarily inadequate public funding for long-term care services in the community.⁵¹ The average Medicaid cost to the Commonwealth of providing home and community based services in 1998

was \$12,780 a year, while the annual cost to provide the same services in a nursing facility was \$31,653.⁵² Accordingly, revisiting some of the policies and practices that keep older adults from obtaining community-based mental health services may result in cost savings while also providing preferred services consistent with people's *Olmstead* rights.

We note that Illinois was recently ranked the fourth worst state in terms of integration of people with all types of disabilities, according to a list compiled by the disability-rights group ADAPT. ADAPT's "ten worst" list was announced on October 8, 2002 and was based on various sources, including state long-term care data and recommendations by advocacy groups.⁵³ The National Conference of State Legislatures reported that in 2001, 86% of Illinois' Medicaid spending on long-term care went to institutional care and only 14% went to home- and community-based services.⁵⁴ For individuals 65 and older, the state had 74.2 nursing facility beds per 1,000 in 1999, compared to a national average of 52.3 beds.⁵⁵

Fragmentation of agency oversight contributes to the difficulty of ensuring that individuals with mental illnesses receive services in the most integrated setting appropriate. Furthermore, advocates also report, the Office of the State Guardian has generally done very little to assist its clients who are inappropriately placed in nursing facilities. Staff of this office reportedly have indicated that they do not wish to create trouble. As the majority of Illinois nursing home residents have no guardian or are clients of the Office of the State Guardian, advocates reported that guardianship is frequently not a helpful tool in assisting individuals to obtain services in more integrated settings.

Providers, advocates and state officials in Michigan all cited as one of the major barriers to developing community-based mental health services for older adults the lack of a public funding stream to support community alternatives. The state's nursing-facilities waiver covers very few individuals with serious mental illnesses because it is geared toward physical health issues. Further, coordination with mental health services does not always happen smoothly and many homebound older adults are not able to access the mental health services that are available. In any event, admissions to the waiver have been frozen. For individuals who do not need a nursing home level of care

but cannot live independently, no publicly funded option now exists to provide the level of care necessary. The Family Independence Agency operates the Home Help program, which provides personal care services to Medicaid recipients, but nothing additional.

Many states might benefit from a targeted Medicaid waiver for older adults with mental illnesses as well as from expansion of Medicaid reimbursement for community options for this population.

Lack of Political Will

Perhaps the most common theme addressed among individuals interviewed in Illinois, echoing statements in Alabama, was the overwhelming political clout of the nursing home industry and the inability to stop unnecessary placement and maintenance of older adults with mental illnesses in nursing facilities. Advocates report that nursing facilities tend to treat individuals with mental illnesses primarily through the use of antipsychotic medication, with little or no accompanying mental health services. The large number of people with mental illnesses in nursing facilities in Illinois—estimated at 27,000—has been the subject of much discussion and recent state legislative hearings.

A number of Illinois' nursing facilities providing intermediate care for individuals with mental illness have been designated as "institutions for mental diseases" (IMDs) because more than half of the residents are individuals with mental illnesses. Federal law prohibits federal Medicaid reimbursement for individuals age 22-65 who reside in IMDs. Therefore, funding for these facilities comes largely out of the state budget. Approximately 6,000 individuals with mental illnesses reside in these IMDs, including older adults under the age of 65.

In Illinois, as in other states, IMDs are effectively a dead-end placement. Few of their residents receive the services they need to make progress. Little or no discharge planning occurs for them and very few are ever discharged. The Department of Public Aid recently promulgated a regulation requiring intensive mental health services for nursing-home and IMD residents admitted for short-term stays for medical reasons related to a mental illness (for example, medication management). Most advocates, while supporting the

goals of the regulation, expressed a great deal of skepticism that it would be implemented effectively, as nursing home and IMD operators have already indicated anger over the cost of providing these services in light of reimbursement-rate reductions.

Limits of Nursing Home Screening

Interviewees in all states noted the limits of preadmission screening and resident review (PASARR)⁵⁶ in keeping individuals with mental illness from being admitted to and maintained unnecessarily in nursing facilities. State standards for determining whether an individual needs a nursing facility level of care are generally very low. Therefore, the ban on admitting individuals who do not need a nursing-facility level of care has not made an enormous difference in the level of nursing home admissions in many states. The PASARR provisions also have their own limitations. They do not cover dementia as a mental illness, and thus individuals with dementia do not receive a PASARR Level II screen unless they have another mental disorder as well.

Disability advocates in Illinois observe that PASARR screeners tend to assess individuals as needing a nursing facility level of care not only because other service options are seldom available but also because the nursing facilities contract with the PASARR agents to perform the assessments. Advocates describe a history of placing people with mental illnesses in nursing facilities based on a primary diagnosis of a physical problem that is not actually significant. One advocate reported having a client in a nursing home whose primary diagnosis was “dandruff” while the secondary diagnosis was schizophrenia.

The intent of PASARR Level II assessments is to determine if an individual who is eligible for nursing home admission actually *needs* that level of care and if care in either a less institutional setting or a more intensive psychiatric program is warranted. Because states have a history of inappropriately benefitting from the Medicaid reimbursement attendant to the trans-institutionalization of people from state psychiatric hospitals and into nursing homes, federal PASARR regulations include the requirement that Level-II assessments be conducted by objective agents independent of the state. Nursing homes, however, also have a

financial stake in preserving their resident populations and there is an inherent conflict of interest in their contracting with the agents conducting these assessments.

Advocates also report that some of the Illinois PASARR screeners do not obtain full information about individuals’ mental health histories, and consequently these individuals do not receive appropriate services in the nursing facility. The advocates say that often this is the result of insufficient time to do complete assessments. Sometimes, they say, preadmission screenings are not done at all. Nursing homes currently face no penalty for a failure to ensure that the screenings are done.

Michigan, however, does conduct a rigorous screening process that keeps many individuals with mental illnesses from entering nursing facilities when they do not need to be there. The PASARR provisions contain an exception to preadmission screening for people who are discharged from a hospital when certain criteria are met and an attending physician certifies that the individual needs fewer than 30 days of care in the nursing facility. Many individuals are admitted to nursing facilities under the 30-day exemption but then are not discharged within 30 days. While the state attempts to keep track of these individuals and require screening if they continue to stay, advocates report that some fall through the cracks and are never screened. One community provider noted that the state has sought to recover reimbursement from nursing facilities that have not ensured screening of residents but does nothing to prevent hospitals from continuing this practice.

Although the Nursing Home Reform Act was amended to eliminate the requirement of annual resident reviews, Michigan admirably continues to have PASARR agents conduct annual face-to-face evaluations of mental health status and service needs. Many residents are determined during these reviews not to need a nursing facility level of care any longer. Nonetheless, because community alternatives are lacking, some remain at the nursing facility. The state OBRA office, which oversees the PASARR program, is making some effort to address this problem. The OBRA office recently sent the community mental health service providers a list of the names of nursing home residents who had been determined not to need a nursing-facility

level of care and requested a review and a placement plan for each individual. Department of Community Health site-review teams are scheduled to follow up on these requests. We hope that other states will follow Michigan's example of using PASARR as a tool to identify and track people who are more appropriately served in more integrated settings. The intent of PASARR, to ensure that people with mental disabilities are not needlessly segregated in nursing homes, parallels the aims of *Olmstead*. It will be important for changes in managed care, such as the policy that now creates a financial incentive for nursing-home placement in Michigan (described above), and fiscal crises in state budgets not to compromise the PASARR process.

Exclusion of Dementia from State Mental Health Programs

Although some (but not most) states have recognized the importance of serving people with dementia as part of the mental health system, several of the states studied have mental health departments that leave it to the aging system to address these individuals' needs. Many older adults in these states go without treatment for their dementia (or co-occurring depression) until they deteriorate to the point where they become eligible for mental health services. PASARR provisions exclude dementia from the definition of mental illness. As a result, many older adults with dementia end up in institutional settings without a preadmission screening to determine if this is the most appropriate and most integrated service setting.

In Nevada, individuals with a primary diagnosis of dementia are not served by mental health department programs and Michigan does not consider dementia to be an element in its mental health system, defined as serving individuals with "serious and persistent mental illness." Although some community mental health programs in Michigan do extend services to older adults with dementia, dementia services are largely provided by the aging system. However, the aging system is generally not equipped to handle clients with serious behavior issues or to deal with accompanying mental health issues such as depression. The state and other states with similar policies should consider modifying the definition of "serious and persistent mental illness" to include dementia.

Conversely, Alabama's community mental health centers do serve individuals with dementia. A number of years ago, the Alabama Department of Mental Health and Mental Retardation created a Bureau of Psychiatry as part of an effort to develop an infrastructure to support both community-based and institutional programs serving older adults with serious mental illnesses and dementia. The Bureau created a long-term care assessment instrument for individuals over age 50 with mental illnesses or dementia; convened town meetings across the state concerning the needs of dementia caregivers; and created the Dementia Education and Training Program, in which it makes available training materials tailored to different levels of understanding and conducts trainings for nursing aides, home health aides, mental health workers, senior services workers and high school and middle school students.

Community mental health centers in Alabama provide some services, including basic living-skill training, that assist individuals in coping with dementia, even though Medicaid reimbursement rates for those services are generally lower than for other mental health services. And Alabama has applied for a Medicaid waiver for specialty assisted-living facilities targeted to serve older adults with dementia. Alabama's nursing-facility waiver serves very few people with serious dementia, as waiver assessments typically note that these individuals cannot be maintained safely in their homes. The assisted-living dementia waiver, if approved, will aim to serve 500 unduplicated individuals in the first year. This waiver will help expand the availability of community services to older adults who cannot live in their own homes. Currently, Medicaid does not fund assisted living facility services. Targeting Medicaid waivers to permit payment for individuals with dementia to live in assisted-living facilities is a positive step. Waivers can also be used to expand eligibility to a wider population by allowing less stringent income-eligibility standards than the standards for state-plan Medicaid services.

Bureaucratic Stumbling Blocks

Many older adults never receive services because they cannot complete the necessary paperwork by themselves and have no access to assistance. In Pennsylvania, for example, some

applicants have been unable to obtain Medicaid benefits because they could not understand the application or swiftly produce the required materials.⁵⁷ County offices have generally failed to provide assistance, instead simply denying applications if documentation is not produced.⁵⁸ One state official referenced a 28-page assessment form required by the Department of Aging. The inability of many elders with mental illnesses to complete this form is treated as a refusal of services. Furthermore, consumers are often expected to navigate the maze of community programs themselves and determine which ones they should apply for.⁵⁹ Agencies providing services to older adults with mental illnesses must ensure that assistance is provided to individuals in completing the application form and securing necessary documentation.

The process of applying for home- and community-based waiver services may take a very long time—in Pennsylvania, sometimes as long as 12 months—before an individual receives services sought.⁶⁰ Many older adults who need a nursing facility level of care cannot wait that long, and instead seek admission to a nursing facility. Nursing facilities often provide immediate access based on an individual’s likelihood of being eligible and assume the risk that the person may ultimately be determined ineligible. They also fill out much of the necessary paperwork themselves. States can use home- and community-based waiver funds to pay for interim services for individuals determined presumptively eligible for waiver services pending a final eligibility determination. Pennsylvania does not do this.

Delays in *Olmstead* Planning

Pennsylvania and Alabama are still in the process of putting together an *Olmstead* plan. While Alabama had projected that its finalized plan would be issued by January 2003, advocates involved in the planning process estimate that it will not be completed for at least another year. Moreover, advocates do not expect many recommendations to be implemented because of the fiscal difficulties the state currently faces.

Michigan has decided not to develop an *Olmstead* plan based on the state’s belief that it is already making

efforts to promote community integration of individuals with disabilities and has been doing so for years. Many advocates disagree with this decision, identifying many steps that the state is not taking to address the unnecessary segregation of individuals with disabilities in a variety of institutional settings.

Illinois issued an *Olmstead* plan in April 2002.⁶¹ The plan contains a section on general mental health planning, which largely describes existing community-based services and programs designed to facilitate community placement for individuals with mental illnesses and discusses some recent initiatives. Providers and advocates involved in the planning process reported that individuals with mental illnesses were given short shrift, with little in the way of new planning done for them. The plan contains few details or timeframes for identifying unnecessarily institutionalized individuals with mental illnesses and developing community services for them. Advocates also note that effective planning would be extremely difficult in light of the state’s refusal to maintain waiting lists to keep track of individuals’ needs for services.

In any event, the Illinois plan contains virtually nothing about the promotion of community integration of older adults with mental illnesses. There is a section on older adults and one on individuals with mental illnesses, but no discussion of the challenges of developing community-based geriatric mental health services. The only reference to planning for this population is a sentence noting that “[t]he Department of Aging will continue to work with [the Illinois Department of Public Aid], and [Department of Human Services] Offices of Mental Health, Developmental Disabilities, Rehabilitation Services, and Alcoholism and Substance Abuse to establish better mechanisms to coordinate comprehensive services for individuals with multiple diagnoses and their families.”⁶² Illinois’ failure to address mental health services for older adults in its *Olmstead* plan is surprising in light of the state’s awareness of the need to address barriers to developing these services.

One Illinois official noted the need for a more practical approach to serving individuals. She commented that much of the planning to move individuals to integrated settings was done without a real under-

Planning that is done on too theoretical a level results in individuals’ failing in community settings.

standing of what each individual would need in order to function in a community setting. Planning that is done on too theoretical a level results in individuals' failing in community settings.

In FY 2001, the Nevada legislature approved funding for a long-term strategic plan to assess the needs of individuals with disabilities and ensure that an appropriate continuum of services is available and that opportunities for independence are maximized. As this development was relatively recent, planning is in the

early stages. The strategic planning process presents a good opportunity for Nevada to look at expanding the array and amount of services provided to older adults with mental illnesses and at the potential for partnerships between the Aging Services Division and the Division of Mental Health and Developmental Disabilities to fund specialized programs that appropriately address the needs of older adults with mental disabilities.

GENERAL RECOMMENDATIONS

While each of the five states we studied has some initiatives that move in the general direction of *Olmstead* goals for older adults with mental illnesses, we found that none has an *Olmstead* process addressing head-on the needless segregation of this population and none has established a comprehensive plan to guide the development of integrated community services. We were particularly interested in whether states were critically evaluating the processes and policies that sustain needless segregation of this population and we hope the recommendations in this report will inspire and assist them in doing so.

In the addendum with descriptions of each state's responses, we offer suggestions to address particular policies and practices that challenge community integration for older adults with mental illnesses in that state. These are meant as a starting point for discussion in these states and in others where these—and other similarly obstructing—policies and practices arise. More generally, we offer the following recommendations for addressing the primary barriers to community integration common to virtually every state.

- **Outreach programs** that target older adults with mental health needs are key to any community-based service system that intends to serve this population effectively. Effective programs require both outreach to isolated seniors who are not part of mental health, aging or other service networks and outreach in places where people receive senior services, such as senior public housing, senior centers and congregate meal centers. Because of the tremendous stigma that older adults often attach to mental health services, outreach efforts must ensure that these services are offered in settings other than traditional mental health settings and that they are made available in a non-threatening, non-coercive manner.

Without coordination at the ground level, it is extremely hard for an individual worker to piece together the fragmented funding streams that support services to individuals with mental illnesses and services to older adults.

- **Coordination between mental health and aging systems** is also extremely important to any effective mental health program for older adults. While partnerships have been formed between mental health agencies and senior services agencies in various local jurisdictions, and to a very limited extent, in occasional state-level efforts, systemic coordination efforts between mental health and aging are generally lacking. Without coordination at the ground level, it is extremely hard for an individual worker to piece together the fragmented funding streams that support services to individuals with mental illnesses and services to older adults. Coordination allows a more holistic approach to older adult mental health services that ensures that all of an individuals' service needs are addressed. Support should be made available to compile centralized sources of information about resources for older adults with mental illnesses, including mental health services, meals on wheels, senior housing, assisted-living facilities and other services. This type of resource would be tremendously helpful to facilitate service coordination by area agencies on aging and others.

Because Medicaid and Medicare are inadequate to support geriatric mental health programs in many areas, effective programs often require joint efforts to pool Older Americans Act funding and state- and county-based mental health funding. Such efforts cannot be undertaken without extensive coordination in planning and administration of programs.

- **A public funding stream** is essential to assure that older adults with mental illnesses can be served in the community and are not forced to enter a nursing home for lack of affordable community options. One problem that must be addressed in most areas is the lack of funding for people who cannot live independently but do not need a nursing-facility level of care. Among other things, Medicaid rules must be flexible enough to

permit people to be served in community settings that provide an appropriate level of care.

Further, states should revisit extremely strict Medicaid eligibility requirements that keep older adults from obtaining community-based services. States might consider developing Medicaid buy-in programs or loosening income-eligibility requirements. Targeting Medicaid waivers to older adults with mental illnesses would also make coordinated service delivery easier and allow the provision of Medicaid services to individuals with income slightly too high for ordinary eligibility.

States should also consider increasing SSI supplements (or other state or local supports) to enable recipients to secure housing.

While all of these strategies involve additional funding, with appropriate planning, these outlays should be offset by cost-savings achieved through the elimination of state expenditures on costly nursing home beds.

- **Training of primary care physicians in geriatric mental health issues** is another important need. This has proven difficult, according to many sources, because doctors have been unwilling and unable to devote time to such training. Nonetheless, it is vital to ensure that primary care physicians have knowledge of appropriate treatment strategies and resources to assist older adults with mental illnesses. Because so many older adults are isolated and unwilling to seek out mental health services on their own, primary care physicians are often their only contact with health care or other systems and offer the only likely avenue for reaching older adults with mental illnesses. Medical school curricula in geriatric mental health, including specific clinical programs and continuing medical education, should be added.

- **Cross-training of mental health and aging services agencies and providers** is also essential to an effective geriatric mental health program. A consistent theme sounded by those involved with geriatric mental health programs across the states is that mental health programs fail to deal effectively with the medical needs of older adults, and senior services programs fail to deal

effectively with individuals with mental health needs. Without an organized, systemic effort to cross-train mental health and senior services providers and advocates, these problems will continue.

- **A centralized source of information** is an important aspect of coordination and cross training. In Alabama, a government bureau devoted to providing comprehensive training and materials on substantive geriatric mental health issues and answering clinical questions has improved coordination efforts. At a minimum, efforts to collect and maintain updated

information about available resources in each area should be supported, so that area agencies on aging, mental health agencies and others have a starting point in efforts to coordinate services for older adults with mental illnesses. Too often providers have no idea where to turn to secure appropriate services for these clients.

- **Inclusion of dementia in mental health programs** is important if community-based services to older adults with mental illnesses are to improve. Aging systems, which have traditionally focused on physical needs of frail elders, are generally ill-equipped to deal with clients with dementia that poses behavioral problems. Advocates confirm that little aging funding is expended on services to assist individuals with dementia in coping and learning adaptive living skills. Moreover, aging services

providers are not generally equipped to recognize the mental health issues that frequently accompany dementia, or to recognize that what is labeled as dementia in seniors is often a manifestation of depression or another mental illness.

- **Redirection of funds** from closure and consolidation of state hospitals is a significant source of resources to expand community-based services for older adults with mental illnesses. While community alternatives are sorely lacking for this population, many states continue to spend large sums to serve older adults with mental illnesses in institutional settings because public funds remain available to support individuals in these settings.

Redirection of funds from closure and consolidation of nursing facilities and state hospitals is a significant source of resources to expand community-based services for older adults with mental illnesses.

CONCLUSION

Our analysis of factors affecting *Olmstead* implementation for older adults with mental illness in this representative sample illustrates the variety of barriers to community integration that are embedded in the structure of public healthcare, licensing and reimbursement systems in every state. Given this nation's long history of exclusion, neglect and degradation of older adults with mental illnesses, it is not surprising to find that these systems have emerged in ways reflecting those negative values. Yet, more than a decade after enactment of the Americans with Disabilities Act and its integration mandate and years after the Supreme Court affirmed in *Olmstead* that unnecessary institutionalization is a form of discrimination, it is disappointing to see how preliminary, limited and tentative states' efforts have been to extend basic civil rights to older adults with mental illnesses.

Older adults with mental illnesses should not be pushed to the end of the line for access to the community integration that is their fundamental right.

The purpose of our study was not to reiterate what is already well-known, the low priority afforded older adults' mental health needs, but to bring to light some of the established policies and practices that sustain their needless segregation and its attendant harms. We hope that our identification of specific barriers and suggestions for reform will inspire local advocates, policymakers and other stakeholders in every state to examine critically why the patchwork of programs affecting older adults with mental illnesses in their localities does not produce the outcomes to which these citizens are entitled, and to initiate meaningful reforms that will ensure them the full membership in their communities to which they aspire—and to which they are by law entitled.

Older adults with mental illnesses should not be pushed to the end of the line for access to the community integration that is their fundamental right.

NOTES

- 1 *Olmstead v. L.C.*, 527 U.S. 581 (1999), holding that unnecessarily institutionalizing individuals with disabilities is a form of discrimination that may violate the Americans with Disabilities Act.
- 2 Also of concern are the barriers to obtaining mental retardation and substance abuse services for older adults. These issues are beyond the scope of this study and report, however.
- 3 *Mental Health: A Report of the Surgeon General*, Chapter Five (1999) [hereinafter "Surgeon General's Report"]. The report may be found at <http://www.surgeongeneral.gov/library/mentalhealth>.
- 4 Administration on Aging, *Older Adults and Mental Health: Issues and Opportunities* (2001), <http://www.aoa.gov/mh/report2001>.
- 5 U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Promoting Older Adult Health: Aging Network Partnerships to Address Medication, Alcohol, and Mental Health Problems (2002), http://www.ncoa.org/mem/promot_hlth.pdf.
- 6 See, e.g., National Conference of State Legislatures, *The States' Response to the Olmstead Decision: A Work in Progress* 7-8 (Feb. 2002), <http://www.ncsl.org/programs/health/forum/olmsreport.htm> ["NCSL Report"]. Some states, such as Michigan, are not working on *Olmstead* plans, believing that they are already complying with the ADA's integration mandate.
- 7 Jennifer Mathis, Community Integration of Individuals with Disabilities: An Update on Olmstead Implementation, 35 *Clearinghouse Review* 395, 406-09 (2001).
- 8 NCSL Report at 7. The states are Missouri, Ohio and Texas.
- 9 NCSL Report at 8.
- 10 Surgeon General's Report, <http://www.surgeongeneral.gov/library/mentalhealth/chapter5/sec1.html>, at 1.
- 11 *Id.* at 1-2.
- 12 *Id.* at 9-11.
- 13 Surgeon General's Report, <http://www.surgeongeneral.gov/library/mentalhealth/chapter5/sec1.html>, at 3.
- 14 Administration on Aging, *Older Adults and Mental Health: Issues and Opportunities* (2001) [hereinafter "Administration on Aging Report"], <http://www.aoa.gov/mh/report2001/chapter1/html>, at 8.
- 15 See 2000 National Census data, <http://www.census.gov/population/www/cen2000/phc-t13.html>.
- 16 Illinois Dep't of Human Services, Office of Mental Health Client Registration Information (Sept. 3, 2002) (statewide summary by age group for period of July 1, 2001 through June 30, 2002).
- 17 2000 National Census Data, <http://www.census.gov/population/www/cen2000/phc-t13.html>.
- 18 Office of Mental Health and Substance Abuse Services Division of Evaluation and MIS, *Data Analysis Report: Community Mental Health Services for Persons Aged 65+, Fiscal Years 1997/1998 through 2000/2001*, at 2-4 (Feb. 15, 2002). These data do not include services funded by private pay, third party insurance payments, and Medicare.
- 19 A Model Geriatric Program for Community Mental Health Centers in Alabama (available through Alabama Geriatric Mental Health Coalition), at Tab J.
- 20 Administration on Aging Report, <http://www.aoa.gov/mh/report2001/chapter1/html>, at 8.
- 21 *Id.*
- 22 *Id.*
- 23 *Id.*
- 24 *Id.* at 9.
- 25 *Id.*
- 26 See 42 U.S.C. § 1396n(c).
- 27 *Id.* at 9-10.
- 28 *Id.*
- 29 *Id.* at 2.
- 30 Surgeon General's Report, <http://www.surgeongeneral.gov/library/mentalhealth/chapter5/sec2.html>, at 1.
- 31 *Id.* at 1-2.
- 32 *Id.* at 9-10.
- 33 *Id.* at 7.
- 34 Surgeon General's Report, <http://www.surgeongeneral.gov/library/mentalhealth/chapter5/sec2.html>, at 7.
- 35 Advisory Committee on Geriatric Services, *Geriatric Mental Health Needs Assessment Report* (Sept. 1997) [hereinafter Advisory Committee Report].
- 36 *Id.* at 3, 6.
- 37 *Id.* at 3, 7.
- 38 Because we received a relatively small number of survey responses, we do not focus extensively on the results of the written survey. Nonetheless, some of the survey responses were remarkably consistent, and we briefly set forth that information.
- 39 The survey asked respondents to rank the following groups in order of the priority they are likely to receive in integration efforts: individuals in developmental centers; individuals age 22-64 in psychiatric hospitals; individuals under age 22 in psychiatric hospitals; individuals age 65 and over in psychiatric hospitals; and individuals in nursing facilities.
- 40 The barriers respondents were asked to rank were: trained workforce, willing community providers, affordable housing, funding, political will, consumer demand, decision makers sensitive to the needs of older adults, evidence-based service models, and any other barriers respondents could identify.
- 41 A Model Geriatric Program for Community Mental Health Centers in Alabama (available through Alabama Geriatric Mental Health Coalition), at Tab J.
- 42 Of course, area agencies on aging do use Older Americans Act money to provide services that enable older adults generally to remain in community settings. The Alabama Cares Program, for example, uses Older Americans Act funding to provide respite care, supplies, transportation and other services to assist caregivers in maintaining older adults in the community. However, few efforts are aimed at addressing mental health needs.

43 *In the Matter of Sullivan*, Case No. V2118594A (Department of Community Health Policy Hearing Authority Decision, May 31, 2002).

44 See, e.g., Pennsylvania Intra-Governmental Council on Long-Term Care, *Home and Community-Based Services Barriers Elimination Work Group Report* (March 2002), at 17. <<http://www.aging.state.pa.us/aging/lib/aging/BarriersEliminationReport.pdf>>.

45 We do not suggest that assisted-living residences are necessarily integrated or appropriate settings for older adults with mental illnesses. Many such residences are institutional and/or not equipped to meet residents' mental health needs. We merely note that allowing waiver services to be provided in more settings—appropriate settings—would expand opportunities to offer the community-based services needed by older adults with mental illnesses.

46 Barbara Coleman et al., *State Long Term Care: Recent Developments and Policy Directions* (July 2002), <http://www.ncsl.org/programs/health/forum/ltc/ltcnv.htm>.

47 As noted in the section below concerning Michigan, the state Medicaid director has recently taken the position that the bulk of the optional mental health services provided in the state's Medicaid managed care program are discretionary services rather than entitlements.

48 2000 National Census Data, <http://www.census.gov/population/www/cen2000/phc-t13.html>; Pennsylvania Intra-Governmental Council on Long-Term Care, *Home and Community-Based Services Barriers Elimination Work Group Report 2* (March 2002) [hereinafter *Intra-Governmental Council Report*].

49 *Intra-Governmental Council Report* at 3.

50 *Id.* at 4.

51 *Id.* at 3.

52 *Id.*

53 See <http://www.adapt.org/bulletin.htm>.

54 Barbara Coleman et al., *State Long Term Care: Recent Developments and Policy Directions* (July 2002). <http://www.ncsl.org/programs/health/forum/ltc/ltcil.htm>.

55 *Id.*

56 The Nursing Home Reform Act in the Omnibus Budget Resolution Act (OBRA) of 1987 requires all individuals with mental illness and mental retardation being placed in nursing facilities to be screened to determine whether they need a nursing facility level of care and whether they need specialized services to address the mental disability. Individuals who do not need a nursing facility level of care cannot be placed in a nursing home. Initially, the law required annual resident reviews to be done in addition to preadmission screening, but that requirement was later eliminated.

57 *Intra-Governmental Council Report* at 7.

58 *Id.* at 9.

59 *Id.* at 8.

60 *Id.*

61 See *Community Living and Disabilities Plan*, at http://www.state.il.us/gov/building/olmstead_intro.cfm.

62 See *id.* at 74.

