



# Transforming Housing for People with Psychiatric Disabilities Report



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
Substance Abuse and Mental Health Services Administration  
Center for Mental Health Services  
[www.samhsa.gov](http://www.samhsa.gov)





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# SECTION I

## INTRODUCTION AND EXECUTIVE SUMMARY

In late 2003, inspired by the recommendations of the President's New Freedom Commission on Mental Health and with funding from the Center for Mental Health Services/Substance Abuse and Mental Health Services Administration (CMHS/SAMHSA), the Judge David L. Bazelon Center for Mental Health Law (hereafter called the Bazelon Center) undertook a study of board and care homes for people with psychiatric disabilities. A draft report on the demographics of board and care homes and a catalog of the incremental measures currently being implemented to improve the lives of residents were produced. On November 18 and 19, 2004, the Bazelon Center then hosted a national strategy meeting to discuss the findings. This event was attended by more than 30 experts from Protection and Advocacy services, mental health associations, national associations of mental health consumers and State mental health directors, alternative housing advocates, and others with a direct interest in the issues. The experts are found in the Participant List on page 49.

This final report incorporates the discussion and recommendations from the November 2004 meeting. Overall, it discusses the impact of short-term quality improvement measures in the use of board and care homes. It also calls for a fresh approach to providing housing for people with psychiatric disabilities—a recovery-oriented approach that revolves around the principles of consumer self-direction and community integration.

Specifically, Section I provides an executive summary of the full report. It summarizes the problems of board and care homes for people with psychiatric disabilities and lists ten recommendations identified at the meeting to improve the quality of life of board and care residents.

An in-depth discussion of the history and demographics and common concerns of board and care homes for residents with psychiatric disabilities are offered in Section II. The next section discusses measures that have been taken to promote integration and good living conditions of persons with psychiatric disabilities in communities. Section IV delineates recommendations for improving the quality of life for board and care residents. The report concludes with a call to end reliance on board and care homes and to improve conditions in existing homes in Section V.

### The Board and Care Dilemma at a Glance

Board and care homes,<sup>1</sup> which are also known as adult homes, emerged as a tentative solution to the problem of housing low-income people with psychiatric disabilities in an environment that offered few alternatives. The lack of stable housing can have a devastating impact on poor people with psychiatric disabilities, so this intermediate approach to housing—intermediate between full institutionalization and integrated community living—was certainly better than the dire alternative of homelessness. Faced with the specter of reinstitutionalization, many State and local mental health authorities either became housing providers or relied on the private board and care industry to house people who no longer needed institutional care, but who did not have sufficient income to sustain housing.

Regulation of board and care homes is left almost entirely to State agencies, and every State has at least one agency that licenses these homes. Licensing focuses on fire safety, sanitation, basic safety, minimum services, staffing, and characteristics of residents who may be admitted. Many such homes have had serious problems providing services or rehabilitative, social, or recreational opportunities.

Reliance on board and care homes needs to be reconsidered. States are relying on them too heavily when more integrated arrangements are possible. Too many of these homes are being managed in ways that barely distinguish them from large institutions. Some board and care homes offer a decent quality of life, having as few as two or three residents in a home-like environment and many features of a normal home life. However, the vast majority of residents in board and care homes do not live in such arrangements. In general, the larger the home—the more it exceeds the number of residents a typical family home would have—the greater the likelihood that it will have an institutional character. That character is directly influenced by the size of the resident population, because among other things, size limits residents' opportunities to interact with people who do not have disabilities.

Even many smaller board and care homes operate like institutions. In these smaller homes, residents are required to line up for their medications and to receive their disability checks; they have little privacy and little choice concerning roommates, meals, or activities; little effort is expended helping them get jobs or job training; and there is no effort to help residents find more integrated housing or to plan their departures. Most problematic is the fact that most residents in board and care homes live with more than 51 residents.<sup>2</sup> In New York, numerous homes house more than 120 residents, and 1 has more than 300 residents, virtually all of whom have psychiatric disabilities. Predictably, these larger homes lack the “environmental features and practices” typical of home-like environments, and life in them is like being in an institution.

A related concern is the isolation from outside contact experienced by residents of board and care homes of all sizes. Often, residents have little or no interaction with people without disabilities, and many lack meaningful opportunities for recreation, leisure, and community involvement. Even the most lavishly decorated, highly regulated board and care home can be in violation of the community integration mandate as clarified by the *Olmstead* decision, and certainly it fails to show a recovery orientation as recommended by the President's New Freedom Commission on Mental Health.

In the mid-1990s, the Federal Government estimated that as many as one million people lived in board and care homes in the United States. The largely privatized board and care industry grew to fill the vacuum created by State mental health systems that failed to develop more integrated services. As of 1991, more than 90 percent of board and care homes were in the private sector, and 63 percent were run on a for-profit basis. National studies estimated that between 32,000 and 34,000 board and care homes, serving about 600,000 residents,<sup>3</sup> were licensed, with an additional 28,000 unlicensed homes serving another 400,000 residents.<sup>4</sup>

Of the total licensed board and care homes, researchers believe that 13.7 percent serve nonelderly adults with psychiatric disabilities.<sup>5</sup> In addition, other studies have suggested that as many as 33 percent of residents in board and care homes overall have diagnoses of mental illness.<sup>6</sup> Unlicensed homes, which are thought to be the fastest growing part of the industry, are more likely to serve adults with psychiatric disabilities than licensed homes. Altogether, it is estimated that as many as 330,000 residents of board and care homes of all types may have psychiatric disabilities.

Little is known about how such homes serve people of any age with psychiatric disabilities. The literature suggests that although there may be regional variations, in nearly every jurisdiction studied the following serious concerns have been raised most often regarding the care of people with psychiatric disabilities: (1) Lack of effective statutory oversight power, (2) poor environmental and physical conditions, (3) civil rights violations, (4) lack of recreational and cultural activities in the community, (5) financial improprieties, and (6) inadequate medical and mental health care. These issues are discussed in more detail in Section II of this report, under the heading “Areas of Concern.”

## The “Transformation Proclamation”: A Consensus Statement on Board and Care Homes

The participants in the national strategy meeting adopted the following consensus statement:

The Americans with Disabilities Act [ADA] and the Supreme Court’s *Olmstead* decision require that state and local mental health agencies provide access to housing and other services in the “most integrated setting” appropriate to the needs of people with psychiatric disabilities. That means a setting that enables them to interact “to the fullest extent possible” with people who do not have disabilities.

We firmly believe that board and care homes serving people with psychiatric disabilities—as currently configured—are generally not consistent with the ADA and the *Olmstead* mandate, and that the overreliance on such homes undermines recovery, community integration and the transformation of the public mental health system called for by the President’s New Freedom Commission on Mental Health. The current system of monitoring, oversight, and licensure does not ensure a quality, recovery-based environment.

Every person with a psychiatric disability deserves a range of housing choices and to live in a home of his or her own. That includes the full rights of tenancy, including a lease, a key, privacy, and the choice of roommate, where relevant.

We believe that state and federal government should take urgent action to ensure that public funds are no longer expended to support segregating living arrangements such as board and care homes. Rather, these funds (including SSI and SSDI disability benefits, state supplements, rent subsidy benefits and funds available from any other federal, state or local source) should be converted into an individual benefit or voucher that will, with any infusion of new money necessary to augment these resources, permit people with psychiatric disabilities to purchase housing of their choice.

This is a matter of highest priority for transformation of the public mental health system. Failing to attend to this matter will diminish the promise of integration for people with psychiatric disabilities and undermine the goal of recovery.

### Summary of Recommendations

Section IV of this report delineates 10 detailed recommendations to SAMHSA for action. The following is a summary of these 10 recommendations:

**1. Incorporate the needs of residents into State *Olmstead* plans and establish reform coalitions.**—Adjust State *Olmstead* plans to ensure that board and care residents are being served in the “most integrated” setting. Also, encourage the formation of State-based reform coalitions in every State—to include residents, resident councils, ombudsman programs, legal advocates, board and care home operators, and other stakeholders—to make comprehensive reviews and recommend housing options.

**2. Increase consumers' options for self-direction.**—Both Federal and State governments should focus on broad measures to increase residents' choice and purchasing power, including these: increasing personal needs allowances; prohibiting board and care operators from acting as representative payees; allowing residents to have control over their own financial accounts to pay for housing and services; and increasing flexibility in Medicaid reimbursement, by using the “rehabilitative necessity” standard. Also, Federal agencies should coordinate their work better with an eye to helping States create action plans and tools to foster consumer-directed services. They should provide money management training and support for residents, earmark housing funds for transition to community living, fund a larger number of peer specialists, and help residents develop their own advocacy skills. Federal and State agencies should more closely coordinate their efforts in this area.

**3. Improve methods of outcome measurement.**—Develop quantifiable outcome measures of the health status and quality of residents' lives, defined broadly. Also, quantify the economic costs of neglect for comparison with the economic costs of moving board and care residents toward recovery.

**4. Strengthen peer support and community outreach and education.**—Earmark grants for peer support and establish peer-run wellness centers in the community. Provide access to health care, education, legal protection and advocacy, and transportation. Connect residents with the mental health consumer movement.

**5. Reaffirm the role of protection and advocacy (P&A) agencies.**—Reaffirm P&A agencies' authority to have direct access to board and care homes. Ensure that State agencies retain their oversight and enforcement responsibilities, and strengthen Federal support for P&A agencies. Encourage these agencies to educate residents about their rights, including *Olmstead* rights, and assist them in forming residents' councils.

**6. Modernize State regulations.**—Every State should create a central registry of board and care homes. States also should provide for easier approval of low-demand, harm-reduction housing; increase the profile of their board and care oversight; increase resident participation in inspections or evaluations; and identify “mandatory reporters” for abuse and neglect concerns.

**7. Expand and clarify the mandate of long-term care ombudsman programs.**—Ombudsman programs should pay closer attention to the needs of board and care residents and should work more closely with P&A agencies.

**8. Enhance access to physical and mental health care.**—Ensure continuity of health care after residence in a board and care home, ensuring that health care coverage is “portable.” Every resident should have wellness recovery action plans. States should fund resident education and skill-building. States should ensure that hospitals are not dumping patients in board and care homes that cannot meet their basic needs.

**9. Strengthen residents' rights.**—State laws should require that board and care residents have the full rights of tenancy. Also, in every State, there should be a bill of rights for residents. The use of seclusion and restraint in board and care homes should be prohibited.

**10. Establish quality improvement measures.**—State oversight agencies should develop incentives for best practices and should develop and enforce licensure standards that require ongoing education and quality improvement plans.

# SECTION II

## THE BOARD AND CARE LANDSCAPE: HISTORY, DEMOGRAPHICS, AND AREAS OF CONCERN

### Introduction

Because of their limited income, many adults with psychiatric disabilities find their housing choices very limited. For the past four decades, public mental health systems in every State in the country have struggled to fill the gap. With the advent of “deinstitutionalization”<sup>7</sup> in the 1960s and 1970s, those systems came face to face with a major dilemma. Hospitals had been “home” to more than half a million mental health consumers in the mid-1950s and had been designed to meet all of their needs. As institutions began to downsize and to close in virtually every State, State mental health authorities faced an urgent need for housing and services in the community:

A large proportion of the chronically mentally ill—in some communities as many as a third or more of those aged 18 to 65—live in facilities such as board-and-care homes. These products of the private sector are not the result of careful planning and well-conceived social policy. On the contrary, they sprang up to fill the vacuum created by the rapid and usually haphazard depopulation of our state hospitals. Suddenly many thousands of former state hospital patients needed a place to live, and private entrepreneurs, both large and small, rushed in to provide it.<sup>8</sup>

Thirty years ago, as psychiatric hospitals began to release patients, board and care homes sprang up as an emergency response, filling a void that neither the community mental health system nor public housing programs were filling. Today, particularly in light of the recommendations of the President’s New Freedom Commission on Mental Health, the mental health community is working with a new paradigm. As the Commission urged, in this new paradigm, it is accepted that every person with a diagnosis of mental illness can recover and can live a full life as a member of the broader community. Because of this new understanding, as well as common deficiencies found in even among the best board and care homes, it is clear that we must foster moving people with mental illness out of these living arrangements and into greater community integration.

One of the promises implicit in the deinstitutionalization movement was that money that supported psychiatric hospitals would be used to sustain mental health patients in the community.<sup>9</sup> But, for reasons discussed at length elsewhere,<sup>10</sup> the money did **not** “follow the person.” Instead, both consumers and State agencies were required to piece together stopgap responses to provide housing and services in the community. As recent exposés in the New York Times<sup>11</sup> and the Washington Post<sup>12</sup> demonstrate, the resulting system of “adult homes” or “board and care homes” has not realized the vision of a community mental health system that supports recovery and community integration.

State agencies place people with psychiatric disabilities in board and care homes.<sup>13</sup> People are moved into board and care homes because it is assumed—though it may also be a hard fact—that “there is nowhere else to put them.”<sup>14</sup> In the mid-1990s, the Federal Government estimated that as many as one million people lived in board and care homes in the United States. National studies estimate that there are approximately 32,000 licensed homes serving about 600,000 residents,<sup>15</sup> with an additional 28,000 unlicensed homes housing about 400,000 residents.<sup>16</sup>

Of the total licensed board and care homes, researchers believe that 13.7 percent serve adults with psychiatric disabilities.<sup>17</sup> Other studies have suggested that as many as 33 percent of residents in such homes have diagnoses of mental illness.<sup>18</sup> Unlicensed homes, which are thought to be the fastest growing part of the industry, are more likely to serve adults with psychiatric disabilities. Thus, as many as 330,000 residents of board and care homes may have psychiatric disabilities.

There are a number of forces at work that will require States to serve current residents of board and care homes in settings that comply with the Supreme Court's mandate in *Olmstead* and the recommendations of the President's New Freedom Commission on Mental Health. But the central focus of this paper is incremental steps to improve the lives of people currently living in board and care homes while a deeper transformation is under way.

The term "board and care home" describes living arrangements that provide shelter, food, and 24-hour supervision or protective oversight and personal care services to residents. Other terms for board and care homes include homes for the aged, residential care homes, adult foster care, domiciliary care and, recently, assisted living facilities.<sup>19</sup> Such homes may be licensed or unlicensed, and range in size from 2 residents to more than 200.<sup>20</sup>

Regulation of board and care homes is left almost entirely to State agencies.<sup>21</sup> Every State has at least one agency that licenses board and care homes.<sup>22</sup> Most licensing focuses on fire safety, sanitation, basic safety, minimum services, staffing, and characteristics of residents who may be admitted. These licensing regimes may or may not include periodic inspections and compliance reviews.<sup>23</sup>

The Federal Government has traditionally played only a limited role in monitoring or regulating the quality of services provided by board and care homes (leaving primary oversight to the States). In 1976, Congress enacted the so-called Keys Amendment to the Social Security Act,<sup>24</sup> which requires States to certify to the U.S. Department of Health and Human Services (HHS) each year that they have adopted and are enforcing standards for board and care homes in which a significant number of residents are receiving Supplemental Security Income (SSI) benefits.<sup>25</sup> Theoretically, the Social Security Administration (SSA) can reduce SSI payments for homes with substandard conditions, but this sanction is virtually never imposed, because it would have the effect of punishing SSI recipients by reducing their benefits. Several commentators have concluded that the Keys Amendment is simply ineffective in improving the quality of housing or care in board and care homes.<sup>26</sup>

State and Federal agencies should certainly be concerned about whether basic living conditions are adequate and should support the goal of recovery for every board and care resident. But these agencies must also focus on whether board and care homes are the "most integrated setting appropriate to the needs" of each person.<sup>27</sup>

### Lack of Response From the Rental Market and Public Housing Agencies

In the private and public housing sectors, housing discrimination against mental health consumers remains a major problem that closes off large segments of the housing market. The persistent problem of NIMBYism ("Not In My Back Yard") has limited the number of units of housing available to consumers.<sup>28</sup> Housing choice for people with psychiatric disabilities has been "limited, often regardless of the individual's financial resources. In many states, people with mental disabilities have been, and continue to be, restricted to the least attractive parts of a community--to neighborhoods where housing is relatively inexpensive and often unsafe."<sup>29</sup> As a consequence, consumers face prolonged hospitalization because of the lack of housing in the community, or are forced into housing that is inappropriate.

Historically, public housing authorities have been unresponsive to the needs of people with disabilities.<sup>30</sup> This lack of response is driven in part by bias and prejudice at the local level, and in part by the Federal Government's underemphasizing access to mainstream public and assisted housing programs.<sup>31</sup>

The lack of stable housing can have a devastating impact on people with psychiatric disabilities. For people whose impairment is episodic, or mild, or for people with sufficient resources, mental illness is often a manageable challenge. For people with serious mental illness who are poor and dependent on the social services system for housing and supports, the effects of their illness can be much more debilitating.

Because of the lack of opportunities in the mainstream rental market, and with Federal support for housing declining, many mental health consumers fell through the cracks of the social services system<sup>32</sup> and were unable to find decent, safe, and affordable housing.<sup>33</sup> The result was an escalation of the number of consumers who found themselves homeless. Faced with this crisis and with the increasing specter of reinstitutionalization,<sup>34</sup> many State and local mental health authorities either became housing providers or relied more heavily on the private board and care industry to house people who no longer needed institutional care.<sup>35</sup> The "privatization" of mental health housing has had profound effects across the country.<sup>36</sup>

## Financing Housing and Community-Based Care

The Surgeon General has recognized that people with severe mental illnesses tend to be poor<sup>37</sup> and that poverty is a risk factor for some mental disorders, as well as a predictor of poor long-term outcome among people already diagnosed.<sup>38</sup> People with serious mental illnesses often become dependent on public assistance shortly after their initial hospitalization.<sup>39</sup> In 1992, the National Institute on Disability and Rehabilitation Research reported that the unemployment rate among adults with serious and persistent mental disorders hovers at 90 percent.<sup>40</sup> As a consequence, people with severe disabilities are nearly twice as likely as those without disabilities to have incomes below the poverty line.<sup>41</sup>

The most significant safety net program, especially for people who do not have substantial work histories before the onset of disability, is the Federal SSI program. In 2004, the Federal SSI benefit was \$552 per month, although 44 States provide modest supplementation—often paid directly to board and care operators—to cover the cost of housing.<sup>42</sup> These payments, known in some States as a shelter allowance, are often variable, depending on the level of supportive and personal care services required.

According to a 2003 study, "the average national rent was greater than the amount of income received by Americans with disabilities from the federal SSI program. Specifically, the average rent for a modest one-bedroom rental unit in the United States was equal to 105 percent of SSI benefit amounts."<sup>43</sup>

Although it is a massive Federal insurance program, Medicaid does not pay for housing, except as a corollary to institutional care or under a waiver. Community-based housing and care for people with psychiatric disabilities is even more complicated because, since 1965, Medicaid has been barred from paying for mental health care for individuals between ages 21 and 65 in Institutions for Mental Disease (IMD). This IMD exclusion applies to any "hospital, nursing facility, or other institution of more than 16 beds, that is primarily engaged in providing diagnosis, treatment, or care of persons with mental diseases, including medical attention, nursing care and related services."<sup>44</sup>

Mainstream funding programs, such as those administered by the U.S. Department of Housing and Urban Development (HUD), are of limited assistance in the financing and development of board and care homes. These homes are eligible for HUD's Section 232 Mortgage Insurance, which is a Government-backed mortgage loan insurance to facilitate the construction and substantial rehabilitation of board and care homes as well as assisted living and other facilities. However, the availability of the Federal insurance or guarantee is of only marginal assistance if the operating revenues are insufficient to cover the debt service.

In sum, poor people with psychiatric disabilities lack the resources necessary to purchase rental housing on the open market and need rental subsidies in order to sustain themselves in the community.<sup>45</sup> When they are unable to find such subsidies, board and care homes become the last resort. In such settings, residents who receive only SSI are typically required to turn over their entire monthly benefit check, and they get back a personal needs allowance of as little as \$25 per month<sup>46</sup> to cover all expenses beyond room and board.

Even in those circumstances in which board and care operators retain \$527 per month of a resident's SSI check, this often is not enough to provide housing, food, and protective supervision for \$17.50 per day.<sup>47</sup> And, as highlighted in the section on personal needs allowances, below, it is exceedingly difficult for residents to move out of board and care settings on their own when they are able to control so little of their own disability benefits.

### Impact of *Olmstead* on Housing for People With Psychiatric Disabilities

On June 22, 1999, the U.S. Supreme Court announced its decision in the case titled *Olmstead v. L.C.*, and set in motion powerful forces that will reshape the way society thinks about housing for people with disabilities. This case, in which the Court held that the unnecessary institutionalization of people with disabilities is a form of discrimination prohibited by the Americans with Disabilities Act (ADA), has been hailed by some advocates as the equivalent of *Brown v. Board of Education*. To understand why, it is necessary to review this nation's history of "housing" people with disabilities.

For the better part of a century, the official policy of the United States was to segregate people with disabilities from "normal" society.<sup>48</sup> Beginning in the late 1950s and early 1960s, a national policy of community living developed, inspired in part by notions of civil rights and human decency and driven by concern about the huge costs of warehousing people in large institutions. The core principle of this "normalization" movement was that individuals with disabilities are entitled to the cultural opportunities, surroundings, experiences, risks, and associations enjoyed by people without disabilities. In housing, normalization means living in a typical size home in a residential neighborhood that offers opportunities for normal social integration and interaction.

Despite this revolution in thinking, the legal protections to ensure equal housing opportunity were slow to develop. Congress passed the Rehabilitation Act in 1973, decreeing that recipients of Federal funds could not discriminate on the basis of disability, but few people understood how these protections should be applied to the housing market. HUD did not even issue the regulations required to implement the law until 1988. In the meantime, discriminatory policies remained firmly in place in public and subsidized housing.<sup>49</sup> Congress passed the ADA in 1990, making an explicit finding that continued institutionalization of people with disabilities was a manifestation of discrimination against them. Congress required the U.S. Department of Justice to promulgate ADA regulations, which went into effect in 1992. Those regulations contain an explicit "integration mandate."



The *Olmstead* case involved two women who were unnecessarily detained in a State psychiatric hospital long after their treating professionals determined they were prepared to live in the community. When the State of Georgia refused to move them out of the institution, citing the lack of community-based housing and supports, the women sued under the ADA. In determining that the ADA required such housing and supports, the Supreme Court said: “[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. . . . [C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” The same principles apply not only to people who are currently institutionalized unnecessarily, but also to people at risk of unnecessary institutionalization because of the lack of community-based housing and supportive services.

The Court ruled that integration is fundamental to the purposes of the ADA and that States are required to provide community-based services rather than institutional placements for individuals with disabilities. The decision has far-ranging consequences for how States provide housing for people with all kinds of disabilities who are currently institutionalized or who are at risk of being institutionalized.

Although the *Olmstead* case involved a State psychiatric hospital, its principles apply equally to any other residential facility, such as: residential school or intermediate care facility for people with mental illness or developmental disabilities, a nursing home, a board and care home, a homeless shelter (to the extent that a State or local government unduly relied on such shelters to house people with disabilities), treatment programs, or a group home.

The search for truly integrated housing models is driven both by concerns over legal liability and by a growing body of research demonstrating the advantage of such alternatives. Liability may arise under the ADA (or the Fair Housing Act). Disability and civil rights advocates have mobilized in virtually every State to press for better efforts to prevent unnecessary segregation, including comprehensive planning and the dedication of new resources to *Olmstead* implementation.

In the 6 years since the Supreme Court’s decision, 40 States and the District of Columbia have established task forces, commissions, or State agency work groups to assess current long-term care systems. Some of these are developing housing plans to support people in integrated settings in the community, but few are very explicit about the steps they will take to bring more housing online. The National Council of State Legislatures reported in 2002 that only a handful of States were taking serious action on the mandate, adopting plans that “contain a clear vision for systems change, specific strategies and goals, agencies responsible for each strategy, timelines and budgets.”<sup>50</sup>

*Olmstead* is influencing housing policy decisions at the Federal, State, and local levels. At the Federal level, the Bush Administration issued Executive Order 13217 in June 2001, requiring HUD and other Federal agencies to “evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities” and to assist States in meeting their *Olmstead* obligations. Although HUD’s initial efforts in this direction have been modest,<sup>51</sup> there will be continuing pressure on the agency to devote substantial resources from its housing programs to help States fulfill the requirements of *Olmstead*.

### President's Commission: Recovery Orientation

In April 2002, President George W. Bush established the President's New Freedom Commission on Mental Health to advance the implementation of the *Olmstead* integration mandate. The crisis highlighted in the Commission's reports has raised the stakes and presents a rare opportunity to reconsider the manner in which public mental health systems provide housing and community-based mental health care. The Commission's *Interim Report to the President* concluded that "the system is not oriented to the single most important goal of the people it serves - the hope of recovery."<sup>52</sup>

Although it did not speak directly to the question of how housing ought to be delivered, it did remark on the centrality of stable housing and identified the ACCESS Program as a replicable model. ACCESS—which stands for Access to Community Care and Effective Services and Supports—was funded by the Center for Mental Health Services as a demonstration project from 1993 to 1998. This program provided funds to enhance services, particularly outreach and case management, for 18 sites in 9 States. One site in each State received additional funds to support system-integration activities, which aimed to create formal working relationships across and between the housing, mental health, health, employment, and education systems. The program resulted in practices that State and local mental health agencies could follow to expand affordable housing opportunities for people with mental illness. The Commission stated that the ACCESS Program demonstrated that even the most vulnerable Americans—homeless people with serious mental illnesses—

can be served through fresh approaches that bring together five distinct service sectors: mental health, drug and alcohol, housing, benefits and entitlements, and medical treatment.... Every policymaker, and nearly every citizen, knows that many people with mental illness are at risk for homelessness. Contributing factors include the lack of appropriate and affordable housing and the lack of access to medications and rehabilitation supports. These are necessary to help people achieve the personal stability that is key to housing stability. Our review finds that ending chronic homelessness, as the Administration has proposed, requires special attention to the adults with serious mental disabilities who are over-represented among the most needy homeless.<sup>53</sup>

### Board and Care Demographics

Much of the national board and care research and literature focus on seniors, with peripheral treatment of people with psychiatric disabilities.<sup>54</sup> To supplement this literature, more limited inquiries concerning people with psychiatric disabilities have been conducted by State agencies<sup>55</sup> and by investigative reporters.<sup>56</sup> Even this literature might be described as episodic, typically responding to a crisis, or media coverage, or litigation.<sup>57</sup>

The *Report on the Effects of Regulation on Quality of Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* noted that—

the niche for board and care homes appears to be different in States with extensive regulatory systems compared with States with limited systems. States with extensive regulatory systems have higher-than-average board and care bed supply and lower nursing home bed supply. Homes in States with extensive regulation have residents with higher levels of disability than homes in States with limited regulatory systems.<sup>58</sup>

The same reported suggested the following:

Findings point to a board and care population that is considerably more frail and disabled than it was 10 years ago. Furthermore, the mix of physically frail elderly, cognitively impaired elderly, and residents with mental illness and developmental disabilities (some of whom are nonelderly) presents a complex caregiving challenge. These factors should prompt a reexamination of the health and safety issues that confront board and care providers and the States' systems for regulating the industry. Of primary importance are the range of services, staffing patterns, and staff training and knowledge needed to meet the needs of today's residents.<sup>59</sup>

Another federally supported study, *Licensed Board and Care Homes: Preliminary Findings From the 1991 National Health Provider Inventory*,<sup>60</sup> reached the following findings:

- Nationally, there were in 1991 an estimated 34,090 licensed board and care homes. Over 90 percent, either for profit or nonprofit, are in the private sector. More than three out of five homes (63 percent) are run on a for-profit basis.
- As a percentage of the total and based on census geographic regions, licensed board and care homes are most concentrated in the West (31.6 percent) and least concentrated in the Northeast (18.2 percent).
- The majority of board and care residents are female (59.1 percent).
- The number of board and care facilities identified by the National Health Provider Inventory (NHPI) is lower than the best previous national listing of board and care homes. A 1991 survey of licensing agencies conducted for the American Association of Retired Persons (AARP) identified approximately 32,000 board and care facilities (Hawes, Wildfire, Lux, & Clemmer, 1993). Adding to this figure, the approximately 4,800 Adult Residential Care Facilities in California omitted from the AARP study yield a total of 36,872 board and care homes. The AARP study, however, did not include facilities licensed by mental health agencies but are included in the NHPI estimate. Because some 15,000 facilities self-identified themselves as homes for people with mental illness or developmental disabilities, the difference in the estimates is significant.
- The NHPI also appears to undercount small homes. A 10-State comparison of board and care facilities by size between the NHPI and the AARP list revealed that the latter identified significantly more homes with 10 or fewer beds. Why the NHPI systematically missed small homes is unclear.
- The data indicate that there were about 34,000 licensed board and care homes in 1991, with over three-fifths run on a for-profit basis. Nonprofits and Government-sponsored board and care homes were more likely than for-profits to serve people with mental illness or developmental disabilities. For-profits tended not to focus on one primary type of clientele.

- Longitudinal data are needed to determine how the board and care industry changes over time. Data are needed on unlicensed homes. The data from the 1991 NHPI confirm that the board and care industry plays a significant role in the housing and care of the frail elderly and other functionally disabled populations.<sup>61</sup>

The study concludes that “[t]here are pressures for expanding the federal role in the oversight and regulation of board and care homes (GAO, 1989). At the state level there is evidence of support for national minimum board and care standards (U.S. Department of Health and Human Services, 1990).”<sup>62</sup>

### Areas of Concern

The research and the collective experience of participants in the November 2004 meeting suggest that there are significant commonalities across the nation concerning the limitations of oversight and the poor condition of many board and care homes. The areas of concern most frequently mentioned include the following:

- **Lack of effective statutory oversight power.**—In New Jersey, a series of reports dating back to 1982 have reported on the failures of the Rooming and Boarding Room Act of 1979. The 1991 Report on Board and Care Reform by the New Jersey Public Advocate concludes with the admonition, “there comes a time when an issue has been so thoroughly investigated and examined that we have a clear understanding of what the problems are and what needs to be done. After a decade of studies and proposals for reform, now is the time to act.”<sup>63</sup> Since that report, there has been no discernible change in the lot of persons with a mental illness who are residing in rooming houses, boarding homes, and Residential Health Care Facilities.
- **Poor environmental and physical conditions.**—In June 2000, the New York State Department of Health evacuated an entire floor of an adult home after conditions deteriorated to the point of becoming dangerous to the residents’ health and safety. Approximately 60 residents were evacuated from the home. Half went to a State psychiatric institution; the other half temporarily moved in with family and friends. These residents were displaced for over 2 months until the operator remedied the conditions.
- **Civil rights violations.**—Two adult homes in New York City were involved in a conspiracy to perform unnecessary surgery on residents for purposes of collecting Medicaid reimbursements and kickbacks. Illinois and Kansas subsidize a number of “secure” nursing homes for people with psychiatric disabilities and limit their freedom to leave the homes. In addition, other congregate facilities are operating under the radar screen, including locked units of nursing homes or board and care homes whose behavioral restrictions (and related sanctions) have the effect of reducing residents’ personal liberty to a minimum.

- **Lack of recreational and cultural activities in the community.**—Lack of stimulation for residents of board and care homes contributes to the sense that such homes have become a form of reinstitutionalization and not a meaningful form of community living. Regular contact with people who do not have disabilities and regular involvement in community activities are major factors in achieving recovery and a sense of integration into the life of the community.
- **Refusal of adult home operators to readmit residents after temporary hospitalizations.**—If residents of board and care homes are not permitted to return after temporary hospitalizations, they are essentially homeless and experience the instability in life and mental health care that other homeless people experience.
- **Financial improprieties.**—Many board and care residents are required to turn over their entire SSI check to the homes' owners or to name them as representative payees. When people with psychiatric disabilities lose control of their own finances and when no governmental agency has effective oversight powers, the conditions for misuse of residents' funds are in place.
- **Inadequate medical and mental health care.**—Although board and care homes are considered nonmedical, because the owners do not provide medical or nursing care, residents often need convenient access to medical and mental health care services. When a State agency places people with psychiatric disabilities in homes that are not staffed by people with some modicum of mental health training, outcomes are likely to be poor.<sup>64</sup>



# SECTION III

## MEASURES TO PROMOTE INTEGRATION AND GOOD LIVING CONDITIONS: EXAMPLES AND FINDINGS

The literature on board and care homes and reports from participants in the November 2004 meeting suggest many of the interventions employed to enhance the lives of board and care residents have not gone far enough. Such interventions have not even been able to achieve their stated objectives; namely, to improve the physical and environmental conditions in such homes. More effective are measures to move residents toward greater independence. Many of the interventions discussed below focus on increasing public scrutiny by creating more “eyes and ears” in board and care homes, whereas others are much more ambitious, such as the Pathways Program in New York that moves people with mental illness into supportive housing.

### Increasing Personal Needs Allowance

People of low income with disabilities, who live in board and care homes, often have little disposable income.<sup>65</sup> Over the past decade, efforts have been undertaken to increase the personal needs allowance (PNA) for such residents because of an understanding that quality of life and community integration can be improved when residents can afford activities in the community.

As part of a community integration effort, the Idaho Ombudsman Program successfully spearheaded an effort to raise the monthly PNA from \$30 to \$40 in the late 1990s. Advocates in Washington, DC, got the PNA raised to \$70 per month in 1991, but because of the political environment, there have been no further efforts for an increase. In Oklahoma, an effort is under way to raise the PNA for SSI recipients from \$30 to \$50 per month.

The Indiana Ombudsman Program has led a campaign for an increase in the PNA; local ombudsmen promoted having facilities invite legislators to the nursing homes and other settings where residents advocated for an increase. A bill to raise the PNA from \$50 to \$52 passed the legislature in 2001, but was vetoed by the Governor because of budgetary constraints. More recently, the New York State legislature has approved legislation to increase the PNA to \$144 per month in 2005 and to \$159 in 2006.

At the national level, in 2000 and 2001 Representative Janice D. Schakowsky (D-IL) introduced SSI legislation that would increase the PNA from \$30 to \$50 for an individual and from \$60 to \$100 for a couple. That legislation was not reported out of committee.

### Study Findings

Research sponsored by the National Long Term Care Ombudsman Resource Center resulted in a December 2001 report<sup>66</sup> that shed significant light on the state of PNAs in several States. The study found that a few States provide a PNA to residents of board and care homes as part of State supplemental funds that are supplied to board and care operators. Of the 28 States reporting data, 21 have PNAs for board and care residents. The study concluded that—

[b]ecause residents in Board and Care homes are typically more independent and better able to participate in activities such as shopping, dining, and visiting, it follows that these residents would need more money for activities, clothing, and expenses. This is reflected in a higher monthly average state allowance for board and care homes (\$56.35)

compared to nursing homes (\$43.29). In more than half of the states providing PNAs to residents of Board and Care facilities, the allowance is higher than that given to nursing home residents.<sup>67</sup>

### Peer Support and Community Outreach and Education

Research over the past two decades has demonstrated that peer support is a critical aspect of a recovery-oriented community mental health system.<sup>68</sup> A number of States have begun using peer support groups in board and care homes to ensure that residents are living in adequate conditions and have the supports and services they need to prosper in the community.

California mental health providers have made extensive use of peer support programs, both inside and outside board and care settings. For example, Transitions Mental Health Association, which serves San Luis Obispo and Santa Barbara Counties, operates the San Luis Obispo North County Clubhouse, located on the grounds of a board and care facility, which aids individuals considered disabled by serious mental illness. This program is based on the social rehabilitation model in which staff and peer supporters help clients in their efforts to develop their interpersonal and independent living skills.

The Mental Health Division of the Health Services Agency of San Mateo County has sponsored a peer counseling program for more than a decade. The county operates a peer counseling college program, and graduates take part in visiting acute and subacute facilities, representing clients at certification review hearings, doing outreach and training for clients at the peer counseling college program and at facilities, and assisting in providing seminars for advanced directives. There is a high priority to review board and care homes in the county to ensure compliance with program requirements and to keep in contact with clients to make sure there are no ongoing problems. Peer Counselors provide peer-to-peer support as well as a client perspective regarding services.

In Lucas County, Ohio a mental health housing agency (Neighborhood Properties, Inc. (NPI)) employs a consumer as a Social/Recreational Assessment Coordinator to foster greater community integration. This coordinator works with consumers who reside in Adult Care Facilities (board and care homes) and supported housing units in that community with an expressed goal of promoting community integration and social opportunities. The coordinator assists residents in accessing recreational activities, encourages their involvement in the consumer-operated center, and assists residents in using the public transportation system. NPI reported that consumers have experienced positive outcomes because of this peer interaction.<sup>69</sup>

As part of the New Jersey Mental Health Redirection Plan,<sup>70</sup> \$250,000 was allocated to improve services to individuals with mental illness living in Department of Community Affairs (DCA)-licensed rooming and boarding homes. The Family Service Association in Atlantic County is being funded to provide training in three regions of the State to owners, operators, and mental health service and county social service providers regarding the impact and ramifications of the Rooming and Boarding Act of 1979. Twenty-one county-based training programs are being implemented to educate provider agencies, social services staff, operators, and owners about services available, and to discuss barriers and methods to improve communications for mutual clients. These programs will be enhanced by the development and distribution of county-based directories of available services. In addition, Family Services is currently conducting a pilot project in each of the 78 licensed board and care facilities in Monmouth and Essex Counties to complete an assessment to assist owners and operators, local mental health providers, and consumer self-help programs in serving the residents. Training needs will be identified and training provided within the residents' homes.

In addition, seven Peer Outreach Support Teams are being funded under the consumer-operated agency Collaborative Support Programs of New Jersey, in Essex, Monmouth, Ocean, Union,



Atlantic, Camden, and Middlesex Counties. These teams are designed to reach out to board and care residents in their homes for visitation, self-help and mutual aid, advocacy and assistance with transportation, socialization, recreation, and referral. Individuals are to be assisted in developing daily living skills, receiving eligible entitlements, becoming involved in the community, and participating in peer outreach training for employment purposes. They are also to be assisted with social outings, meetings, and group activities. The teams provide this assistance in order to increase the level of socialization and connection to necessary support systems.

A related program, called Shore-Easy, was a \$10 million program carried out in coordination with the Departments of Health and Senior Services (DHSS) and Community Affairs (DCA), and the New Jersey Housing and Mortgage Finance Agency (HMFA), to provide the resources and the administrative framework needed to purchase and close substandard congregate care facilities in targeted shore communities. This program included a plan to move residents displaced by those closings into adequately supported settings in locations throughout the State.

As a result of the Shore-Easy initiative, a total of 250 beds of questionable quality were closed, and 215 individuals residing in 5 facilities were relocated. One hundred and fifty-one (70 percent) of those individuals initially moved to locations outside of the Shore-Easy communities, and 64 remained. All persons relocated to other settings were individually assessed, provided choices for replacement locations and facilities, and linked to the case management and supportive mental health services that each required. Facilities closed by this initiative were purchased by the HMFA, and procedures were implemented for redevelopment in cooperation with local officials in the communities affected.

Advocates in New York have also pressed for greater use of peer advocates for board and care residents. The Peer Bridger model developed by the New York Association of Psychiatric Rehabilitation Services is designed to recruit and train people who have experienced psychiatric disabilities to assist others in staying out of the hospital and maintaining themselves in the community.<sup>71</sup> The New York Adult Care Facilities Workgroup has recommended that Peer Bridger services be made available to every mental health consumer who requests them.<sup>72</sup>

Similarly, Connecticut's Peer Engagement Specialist Program,<sup>73</sup> which was authorized in 2000 to provide innovative means of reaching hard-to-serve people with psychiatric disabilities, has played a role in getting consumers engaged in stable housing and services. Although there has not been a mandate to become involved in board and care homes, the existence of this program provides a platform on which such Peer Engagement Specialists can be used in those settings.

## Protection and Advocacy Agencies

Under legislation known as the Protection and Advocacy for Individuals with Mental Illness (PAIMI) Act,<sup>74</sup> Congress granted special legal authority to State protection and advocacy (P&A) systems, authorizing their access to clients and records for the purpose of conducting independent investigations to redress and prevent abuse, neglect, and rights violations in various types of public and private facilities, including board and care homes. Every P&A may address issues that arise for individuals with mental illnesses who reside in a psychiatric hospital or who live in the community.<sup>75</sup>

P&A agencies provide advocacy services for individuals with disabilities, including representing individuals in administrative and judicial proceedings to protect their legal, civil, and service rights, especially under the ADA and Section 504 of the Rehabilitation Act of 1973; filing impact litigation; telling individuals with disabilities about their legal, civil, and service rights and about ways to enforce those rights; referring individuals to other sources of help; providing support and

training for individuals with disabilities, their families, and advocates; reaching out to underserved communities; and providing information about disability issues to Government officials.

With the establishment of its Health Advocacy Project in 2003, Protection & Advocacy, Inc. (PAD), the statewide P&A for California, has launched a pilot project, funded by the California Endowment, to increase board and care residents' access to health care. The project will begin in San Diego. At present, there is no funding available to expand the outreach to other parts of the State.

### Vouchers and Regulation

Colorado has chosen to require extensive regulation of assisted living residences (formerly known as personal care boarding homes<sup>76</sup>) and has begun to experiment with direct payments through vouchers. These vouchers permit some people with disabilities to purchase their own services and help residents of long-term care move out of congregate settings and into more integrated settings in the community, such as apartments and shared housing. The extent to which these approaches will benefit younger people with psychiatric disabilities is not yet known.

For those who remain in assisted living residences, the State licensing agency requires a written board and care plan for every resident, which must be reviewed at least annually. Operators must provide a physically safe and sanitary environment, room and board, personal services (transportation, assistance with activities of daily living and instrumental activities of daily living, and individualized social supervision), protective oversight, and social care.

A copy of the resident agreement must be provided upon move-in. The agreement must include: admission, retention, and discharge policies; charges, refunds, and deposits; service included in the rates and charges; services provided by the facility, services not provided, and services that the facility will help the resident obtain; a board and care plan outlining functional capability and needs; resident rights, grievance policies, and house rules; and policies for managing personal funds. Homes that offer "secured" environments must disclose to the resident or her or his legal representative, before admission, that the environment is secure and the types of diagnosis or behaviors the staff are trained to address. State regulations also prescribe staffing ratios, education and training for administrators and front-line staff, and background checks for all persons responsible for the care and welfare of residents. Regulations also specifically reinforce the right of access by the State Long-Term Care Ombudsman Program.

### Study Findings

The most significant study of the effect of State board and care regulation on the quality of care is the 1995 report commissioned by HHS, titled *Report on the Effects of Regulation on Quality of Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (hereafter called the HHS Study).<sup>77</sup> It tested the hypothesis that more extensive regulation would have overall positive effects on board and care homes delivering supports and services to residents with disabilities. The study assessed the effects of State board and care home regulations on the quality of care provided by those institutions. Investigators also attempted to identify the characteristics of the board and care environments in the States selected for the study and to determine whether or not licensed and unlicensed homes differed in terms of those characteristics or in the quality of care provided. Its essential findings are the following:

- There are approximately 34,000 licensed board and care homes in the United States, falling into one of three basic types of licensed facilities: those serving people with developmental disabilities; those serving people with mental illness; and those serving a mixed

population of physically frail elderly, cognitively impaired elderly, and persons with mental health problems.

- Both regulation and licensure have positive effects on the quality of care in board and care homes. States with extensive regulatory systems had a significantly smaller proportion of unlicensed facilities than States with limited regulation (7 percent vs. 25 percent). Extensive regulation also had a positive effect on several quality-of-care and quality-of-life indicators, such as lower use of psychotropic drugs and medications contraindicated for the elderly, more operator training, and greater availability of social aids (e.g., reading materials and community rooms) and supportive devices (e.g., grab bars in showers and call buttons in bathrooms).
- Licensure also had a positive effect on many of the quality-of-care measures explored. For example, licensed homes were more likely to have operators with training and to make more social aids and supportive devices available to residents. Licensure also enhanced the availability of key services and the prevalence of safety features. Licensed homes were less likely to have the lowest scores on such measures as availability of social aids, physical amenities, safety features, and an environment with little diversity and a very institutional atmosphere.
- Neither extensive regulation nor licensure had a positive effect on some aspects of quality, including a requirement for preservice training of staff and staff knowledge of care, monitoring, and medication management.
- Regulation also had no significant effect on the cleanliness of homes and on the availability of amenities or the likelihood that a home would have any licensed nurses (registered nurses or licensed practical nurses) on staff. Furthermore, there was little variation among homes on such issues as unmet health care needs, residents' rights, and indicators of resident satisfaction.

The findings of the HHS Study are largely echoed in two previous<sup>78</sup> and two subsequent<sup>79</sup> studies conducted by nongovernmental groups.

Research funded by the Robert Wood Johnson Foundation found that residents receive a greater **quantity** of health and social services in larger homes and those licensed by the State, but regulatory stringency does not affect the **quality** of services they receive. Research completed in 1994 by the Brown University Center for Gerontology and Health Care Research<sup>80</sup> (and funded by the Robert Wood Johnson Foundation) found the following:

- Licensed homes tend to be smaller facilities with more direct care staff per resident than unlicensed homes. They provide slightly more health-related services (2.22 services, vs. 1.78) and social services (3.87 vs. 3.50) to residents and are more likely to have arrangements with outside agencies for resident services.
- Homes in States with strong regulations were more likely to serve an exclusively elderly clientele.

### Ombudsman Programs

Recognizing the need for an independent agency to investigate complaints in long-term care settings, Congress authorized and funded long-term care ombudsman programs under the Older Americans Act.<sup>81</sup> In 1981, Congress expanded the mandate of the ombudsmen to cover board and care homes and required such programs to maintain a ratio of 1 paid staff member for every 2,000 beds in the jurisdiction. By 1996, more than 17 percent of complaints to ombudsman programs concerned board and care homes.

In California, where there are nearly 30,000 residents in more than 2,700 licensed board and care homes, there are no fewer than 40 California statutes or codes that reference the Long-Term Care Ombudsman. As such, the duties are highly defined, including those in the area of board and care residents with psychiatric disabilities. State law requires social service agencies that provide services that may overlap with those of the Ombudsman to coordinate efforts with the Ombudsman.<sup>82</sup> PAI has coordinated efforts with the Ombudsman, in its investigations unit and in several special projects that are designed to maximize public scrutiny of conditions experienced by board and care residents.

Colorado has adopted detailed guidelines for its ombudsman program to survey board and care plans. State law requires a written board and care plan for each resident at the time of admission, which must identify the resident's needs and the services that the facility will provide to meet those needs. The intent of the regulation is to ensure that the written information accessible to the care provider describes the resident's need for help with daily routine as well as limitations so that staff can provide necessary services. In addition, the Ombudsman has produced an educational video, "Residents' Rights in Board and Care," for residents, their families, and caregivers.

In Georgia, the State Long-Term Care Ombudsman has worked closely with Atlanta Legal Aid on education and advocacy efforts related to board and care homes.<sup>83</sup> In addition, the Gerontology Institute at Georgia State University has undertaken research on the special needs of board and care residents of low income, including those with psychiatric disabilities. The Georgia program has an extensive complaint resolution process, and it reports the findings of its investigations online for public scrutiny.<sup>84</sup>

A Kansas statute<sup>85</sup> establishes the Long-Term Care Ombudsman as an independent agency, with no authority over the Ombudsman by any other State agency. The statute was amended in 1998 to include this language, in response to perceived conflicts of interest by being associated with the Department of Aging. Another statute<sup>86</sup> describes the duties of Long-Term Care Ombudsman with respect to advocacy for people with mental illnesses and developmental disabilities, in addition to the elderly. This statutory scheme is held out as a national model for describing expansive duties in an agency that is free from outside influence.

Louisiana's Long Term Care Ombudsman Program covers residents of nursing homes, board and care facilities, and skilled nursing facility units of hospitals in 22 parishes, who need assistance with protection of rights or quality-of-life issues. A separate program, the Ombudsman Legal Assistance Program serves these same populations with respect to legal assistance regarding residents' rights, abuse and neglect, legal status, and public benefits. The governing statute<sup>87</sup> places an emphasis on microinvolvement, including that the Ombudsman is to facilitate communication between residents' families and the facility. The statute gives broad authority, including anything that the Ombudsman deems necessary.

New Mexico's Long Term Care Ombudsman Program (LTCOP) has 5 staff people who serve as Regional Ombudsman Coordinators and 130 trained and certified Volunteer Ombudsmen. Collectively, they are responsible for coverage of 213 licensed residential care facilities that can provide care for as many as 4,170 residents, in addition to a much greater number of nursing

facilities. The LTCOP added an attorney to its staff in 2003. The attorney works on right of access to facilities. Any person who denies access to the LTCOP or interferes with its investigation of complaints is subject to a civil penalty of as much as \$5,000 to \$10,000 per occurrence.

In Washington State, by statute<sup>88</sup> a nonprofit agency must provide Long-Term Care Ombudsman services. This requirement surfaced in 1998, when serious questions were raised regarding the Department of Social and Health Services' ability to perform the Ombudsman functions.

## Exemplary Programs

Studies conducted since 1996 by the Administration on Aging (AoA) indicate that the States with greatest Ombudsman activity have been Kansas, Louisiana, Maine, New Mexico, Oregon, Pennsylvania, Washington, West Virginia, and Wisconsin.<sup>89</sup>

The success of such programs and their need for support was recognized in 1988, when the AoA requested proposals to develop a National Center for State Long Term Care Ombudsman Resources. The 1992 Older Americans Act amendments added a new provision<sup>90</sup> requiring the AoA to establish a permanent National Long Term Care Ombudsman Resource center. That center, operated by the National Citizens' Coalition for Nursing Home Reform (NCCNHR), maintains an extensive Web site,<sup>91</sup> technical assistance resources, and an extensive curriculum for training and enforcement purposes. Exemplary programs from Alaska, California, Georgia, West Virginia, and other States have been compiled into a comprehensive curriculum manual, which is available online.

## Enhancing Access to Physical and Mental Health Care

### Study Findings

It has been known for some time that poor physical and mental health can be associated with poverty and unstable housing conditions. One method of enhancing quality of life is to make connections between board and care homes and community health agencies. The research cited earlier by the Brown University Center for Gerontology and Health Care Research<sup>92</sup> resulted in these findings:

- Facilitating connections between board and care homes—particularly small, unlicensed homes—and outside agencies may be a more effective way to enhance the quality of care than creating extensive regulation.
- Eighty-two percent of community service agency representatives surveyed said they had no agreement with board and care homes to serve their clients, although some stated they did have a mandate to monitor residents. Most operators of board and care homes, however, report that homes do have arrangements with outside agencies to provide services. This inconsistency suggests that many homes do secure outside services for residents. However, structural linkages of community service agencies and board and care homes are rare.
- Fifty-one percent of service agencies felt that a formal agreement to provide services for all residents of a board and care home would not help improve the quality of care in board and care homes, whereas only 21 percent thought it would. Almost all (97 percent) felt such an agreement could not substitute for inspections by a regulatory agency.

- Size of home does not appear to influence the number of health-related services provided directly by the home.
- Board and care staff who assist with drug administration typically have no medical training in drug management. Yet, most older residents of homes routinely take multiple prescriptions and over-the-counter drugs, and many take prescribed drugs considered inappropriate for the elderly. Psychoactive drug use rates are high. Drug management is somewhat better in licensed homes located in States with more stringent regulation of homes, but still far below what should be expected of licensed board and care homes.

### Residents' "Bill of Rights" Approaches

Many States have established a bill of rights for residents of adult care or assisted living homes. One of the most comprehensive is that established by statute in North Carolina.<sup>93</sup> It guarantees residents the right to—

- Be treated with respect, consideration, dignity, and full recognition of his or her individuality and right to privacy;
- Receive care, and services that are adequate, appropriate, and in compliance with relevant Federal and State laws and rules and regulations;
- Associate and communicate privately and without restriction with people and groups of the resident's choice on his or her own initiative at any reasonable hour;
- Be encouraged to exercise rights as a resident and citizen and be permitted to make complaints and suggestions without fear of coercion or retaliation;
- Manage his or her personal needs funds unless such authority has been removed; and
- Have freedom to participate by choice in accessible community activities and in social, political, medical, and religious resources and have freedom to refuse such participation.

Clearly, these provisions transcend mere regulation of conditions and mental health services. In statute, at least, they recognize the right of residents to make their own decisions and guarantee access to the community. Unfortunately, the statute does not establish a private right of action to complain of violations; enforcement depends on administrative complaints to a State agency.

Two other States with similar bills of rights are Minnesota<sup>94</sup> and South Dakota.<sup>95</sup> South Dakota, by State regulation, requires such homes to inform residents of their rights and to provide information on available services. This State also allows residents to manage their own financial affairs and to have a choice in care planning. The regulations also provide for privacy and confidentiality; quality-of-life measures; a grievance process; and certain rights concerning admission, transfer, and discharge policies.

## Provider Quality Improvement Measures

In addition to efforts by State agencies to set minimum criteria and provide for monitoring and oversight, quality improvement measures taken by the board and care industry itself are an important complement. Although board and care home operators have no formal body such as the Joint Commission on the Accreditation of Health Care Organizations or the Continuing Care Accreditation Commission to carry out accreditation activities, a number of informal bodies have arisen.

The *Board & Care Quality Forum*, a bimonthly publication of Reisacher Petro and Associates,<sup>96</sup> provides a forum for board and care operators to discuss concrete measures that can be taken to improve conditions and resident outcomes, even in cases involving homes for people of very low income. The *Forum's* editorial board is drawn from the provider community, lawyers, family advocacy groups, practitioners, academics, and ombudsmen.

Recent issues of the *Forum* have featured articles on resident autonomy,<sup>97</sup> challenges faced by operators who want to set priorities for community integration,<sup>98</sup> confidentiality,<sup>99</sup> and recovery from mental illness.<sup>100</sup> The breadth of these articles, and the accompanying “idea exchange” and “resource corner” features, suggests that a segment of the board and care industry is actively engaged in promoting improvements. Efforts to improve the lives of board and care residents ought to take into consideration the participation and views of those associated with the *Forum*.<sup>101</sup>

## State-Based Reform Coalitions

The New York State Coalition for Adult Home Reform (NYSCAHR) brings together social services, disability and legal advocacy groups, and people living in adult homes. This coalition, which has had an impact on the State's efforts to improve conditions for people with psychiatric disabilities living in adult homes, holds monthly meetings with State officials to discuss adult home issues, arranges meetings between residents and policymakers, and sponsors an adult home resident *Speak Out* each year. At the *Speak Out for Dignity, Respect and Choice*, residents present the legislative agenda they have developed and meet with members of the legislature to advance that agenda.

NYSCAHR's efforts have kept adult home reform on the radar screen for policymakers. In 2004, responding to the reduction of the previous fiscal year budget for reform efforts, the coalition proposed a broad-ranging package of interventions designed to address the structural problems facing residents of adult homes. The coalition's recommendations included—

- Funding for housing: \$100 million in State capital with no required match for 1,000 additional units of housing for adult home residents; \$41.25 million for 2,500 scattered-site housing units. The units proposed here would include extra funds for the housing provider to hire additional case managers. The cost per unit is \$16,500; \$500,000 would be used to support a housing application assistance office designed to assist people with psychiatric disabilities who currently live in adult homes in paying for housing.
- Legislation to establish a New York State Office of Mental Health (OMH) Housing Waiting List, which would provide the data necessary for the development and deployment of community housing for people with psychiatric disabilities. This list should include all adults with psychiatric disabilities who have applied for but not received supportive, supported, supervised, or congregate housing.

- Case management services provided by teams of professionals and peers, funded at \$15 million annually to cover the State's share of the Medicaid match.
- Implementation of a Medication Management System, funded at \$5 million annually to cover the State's share of the Medicaid match.
- Resident assessments. Funds are needed to continue implementation of individual assessments of people currently living in adult homes. The Department of Health has enough money to complete only 2,500 assessments in 19 New York City homes. The assessments have demonstrated that residents have the capacity to live in supported housing and other community settings. More than 30,000 people reside in 500 homes throughout the State.
- Legal and lay advocacy, funded at \$1 million annually, to help ensure that residents of adult homes know about and are able to enforce their rights.
- Peer specialists, funded at \$4.8 million annually, to ensure that all 12,000 people with psychiatric disabilities in adult homes have access to peer support.

Each State will have different issues concerning the well-being of board and care residents with psychiatric disabilities, but the coalition's advocacy provides a template<sup>102</sup> for reform efforts in other jurisdictions.

### Lawyer/Organizer Model of Advocacy

MFY Legal Services, Inc., is funded by State and local government agencies and private foundations to address the legal needs of adult home residents in New York City. MFY's Adult Home Advocacy Project is run as a partnership with the Coalition of Institutionalized Aged and Disabled (CIAD), and does outreach to and education of adult home residents, including organizing and empowering resident councils. Project staff are in the homes regularly. The project seeks to develop relationships with residents and to use advocacy, litigation, and media work to bring attention to the problems and secure redress for the residents.

### More Integrated Settings

Pathways to Housing, in New York, has demonstrated that even people with the most severe mental disabilities can live in supported housing, even people coming in directly off the street, and even in an expensive market like New York's.<sup>103</sup> A key has been the provision of comprehensive, but entirely **voluntary** mental health, addiction, and other services. Pathways "allows clients to determine the type and intensity of services or refuse them entirely."<sup>104</sup>

The Pathways program has worked with homeless individuals who live on the streets and have psychiatric disabilities or substance addictions and has helped them obtain independent housing without requiring treatment first. An evaluative study of Pathways, which compared its clients' rate of housing retention with that of homeless people in a comparison housing program that required its clients to participate in psychiatric treatment and maintain sobriety first, found the following:



After five years, 88 percent of those in the Pathways program and 47 percent of those in the comparison group remained housed....[T]enants of the Pathways program achieved greater housing tenure than those in the linear [comparison] residential treatment settings when the analysis controlled for the effects of the other client variables in the equation. Specifically, the risk of discontinuous housing was approximately four times greater for a person in the linear residential treatment sample than for a person in the Pathways program.<sup>105</sup>

Most important, “[f]or the homeless clients in these programs, living in apartments of their own with assistance from a supportive and available clinical staff teaches them the skills and provides them with the necessary support to continue to live successfully in the community.”<sup>106</sup>

A number of other communities have developed outreach, services, and housing programs that have proven effective with treatment resistant or hard-to-serve clients. These communities have implemented them with virtually no coercion. During the past 5 years, under the rubric of Assembly Bill 34 (AB 34) programs, the California Department of Mental Health has funded innovative outreach and engagement practices that have shown significant promise.<sup>107</sup>

## Study Findings

Reliance on congregate models has led to poor-quality housing in many States,<sup>108</sup> and consumer preference studies consistently indicate that people with psychiatric disabilities prefer not to live in isolated, congregate settings, such as board and care homes.<sup>109</sup> A study by the National Alliance on Mental Illness of New Jersey (NAMI New Jersey) revealed that although less than .06 percent of respondents surveyed preferred board and care homes as long-term housing settings, they had few other options.<sup>110</sup> Other research has suggested that outcomes for people with psychiatric disabilities are better in supportive housing than they are in group homes or board and care homes.<sup>111</sup>

Research indicates that people with even very severe psychiatric disabilities (and, in many instances, co-occurring substance abuse problems) can be successfully placed in independent housing that complies with the ADA and the *Olmstead* mandate, leading to significantly better outcomes.

We know that poor housing is correlated with poor community adjustment outcomes,<sup>112</sup> and that residents of supportive housing experience stability in housing, greater satisfaction, and a dramatic reduction in hospital days.<sup>113</sup> Greater choice in housing is also positively correlated with happiness and life satisfaction ratings and, ultimately, with community success.<sup>114</sup> Indeed, client preference may predict success in different housing options better than any other single criterion.<sup>115</sup>



# SECTION IV

## RECOMMENDATIONS

State-based advocates and policymakers have begun to realize the implications of Olmstead for housing policy for people of low income with psychiatric disabilities.<sup>116</sup> As they assess how to apply limited resources to meet their obligations under *Olmstead*, they will need to determine the utility of improving board and care homes, as opposed to replacing them with the more integrative model of supportive housing.

Without question, the main thrust of participants' concerns at the November 2004 meeting was to end reliance on board and care homes for people with psychiatric disabilities by 2010. This goal cannot be achieved without a primary emphasis in State mental health policy on the development of integrated housing options. This effort will require an increased willingness to move away from congregate models that house only people with psychiatric disabilities. Such outdated approaches merely substitute mini-institutions in the community for the larger institutions that have traditionally served people who rely on the public mental health system.

Between the present and 2010, participants at the November 2004 meeting offered the following additional recommendations for concurrent measures to improve the quality of life of board and care residents:

### **1. Incorporate the Needs of Board and Care Residents Into State Olmstead Plans and Establish Reform Coalitions**

- **Adjust State Olmstead plans.**—Because the principles of Olmstead require States to consider the needs of all people who are in settings that are not the most integrated, State plans should address the needs of board and care residents. In this way, States will fulfill their legal obligations and move toward the vision of recovery and community integration outlined by the President's New Freedom Commission on Mental Health.
- **Encourage State-based reform coalitions.**— Every State should be encouraged to form a coalition—to include residents, resident councils, ombudsman programs, legal advocates, board and care home operators, and other stakeholders—who will recommend housing options. These coalitions should carry out comprehensive reviews and should make recommendations for expanded options to make affordable housing more available and to make voluntary, flexible services available in the community.

### **2. Increase Consumers' Options for Self-Direction**

Federal and State governments should focus on broad measures to increase the choice and purchasing power of residents, including these:

- **Increase personal needs allowances.**—The more discretionary funds a resident has, the greater her choice and autonomy, both inside and outside a board and care home.

- **Expand the “money follows the person” approach.**—Prohibit the practice of board and care operators acting as representative payees. Rather than allowing board and care home operators to control residents’ disability checks, establish accounts over which residents have control and which they can use to pay for housing and services. In addition to SSI and SSDI benefits and State supplements, these accounts might be modeled on the “individual development accounts” being offered to Temporary Assistance for Needy Families (TANF) recipients or the Family Self-Sufficiency Accounts available to participants in many Section 8 housing programs.
- **Increase flexibility in Medicaid reimbursement.**—Federal and State agencies should explore the creative use of Medicaid waivers and options and more aggressively use the “rehabilitative necessity” standard for reimbursement of services related to recovery from mental illnesses.
- **Seek better coordination between Federal agencies.**—CMHS/SAMHSA and the Center for Medicare and Medicaid Services (CMS) should work together more closely, with an eye to helping States create action plans and tools to foster consumer-directed services.
- **Provide money management training and support.**—Train residents in money management as part of the skill-building necessary to support their living successfully in the community and moving toward recovery from mental illness.
- **Earmark housing funds for transition to community living.**—Earmark Section 8 or other rental assistance funds for transition from board and care homes. Assistance levels should be pegged to the “fair market rents” calculated by the U.S. Department of Housing and Urban Development (HUD) and should provide for security deposit and utility connection deposits. HUD’s recent issuance of PIH Notice 2005-05 acknowledges the difficulty experienced by people with disabilities in finding appropriate housing in the community. This Notice also permits a local housing authority to increase housing allowances to make more units available to people with disabilities.
- **Fund additional peer specialists.**—Fund a larger number of peer specialists and provide flexibility in Medicaid reimbursement practices. With these steps, residents can have more frequent, more meaningful interactions with peer specialists, and their contact with them is not overwhelmed by handling paperwork, which tends to disrupt the building of trust.
- **Help residents develop their own advocacy skills.**—Provide training and support to allow residents to speak to policymakers and enhance their voices and ability to speak on issues that affect them most.

### 3. Improve Methods of Outcome Measurement

- **Quantify outcome measures that are reliable and objective.**—Develop new methods of quantifying outcome data and measuring improvements in the quality of residents’ lives. These outcome

measures should be reliable and objective. To the extent feasible, the information base should be developed through neutral surveys with extensive consumer input by evaluators who are independent of funders, homes, and providers.

- **Define outcome measures broadly.**—Outcome surveys must measure, by objective standards, residents' autonomy, decisionmaking, choices, community involvement, spiritual life, emotional life, and so on.
- **Quantify the economic costs of neglect and the economic value of community integration.**—The costs of neglect should be quantified as well and measured against the direct expenditures of moving board and care residents toward recovery. Also, just as avoidance of jail, prison, emergency rooms, psychiatric hospitals, and homelessness has been determined and factored into public policy, so should the positive economic value of placing people with psychiatric disabilities into the most integrated setting appropriate to their needs.

#### 4. Strengthen Peer Support and Community Outreach and Education

- **Establish peer-run wellness centers in the community.**—Provide access to health care, education, legal protection and advocacy, and coordination and transportation.
- **Earmark peer support grants.**—The CMHS Systems Change grants prioritized peer support and described it as the cornerstone of any recovery-oriented approach.
- **Connect board and care residents with the mental health consumer movement.**—Encourage and enable visits to board and care residents by mental health consumers who have become educated about disability rights laws. Often working through Independent Living Centers, local offices of Mental Health Associations, and Homeless Outreach Centers, individuals with mental illness can provide invaluable support and education to others with mental illness. The first steps needed to increase the involvement mental health consumers with board and care residents are more funding for peer support groups, targeted outreach to board and care homes, and onsite visits.

#### 5. Reaffirm the Role of Protection and Advocacy (P&A) Agencies

- **Reaffirm P&A agencies' access to board and care homes.**—Federal agencies should issue guidance reaffirming that P&A agencies have the right of access to all community-based settings, including board and care homes, as a means of fulfilling their mandates under Federal law.
- **State agencies must retain oversight.**—State regulatory agencies should not abdicate their oversight roles simply because the P&A agency has access to board and care homes; oversight and enforcement must remain the responsibilities of licensing and oversight agencies.

- **P&A agencies should educate board and care residents on residents' rights.**—P&A agencies should provide training on the rights of board and care residents and assist them in forming board and care residents' councils.

### 6. Modernize State Regulations

- **Create a central registry of board and care homes.**—A central registry could be created by SAMHSA, with cooperative input from State licensing agencies. Alternatively, each State could be required to create its own central registry, following standardized rules, which a Federal agency could then combine into a national registry.
- **Update State regulations.**—States should update their regulations to provide for easier approval of low-demand, harm-reduction housing and services models.
- **Increase the profile of board and care oversight in States.**—States should increase their oversight and make it more transparent. Every board and care home should be inspected, periodically, through unannounced site visits by teams who include individuals with mental disabilities and their advocates. Inspections should measure both physical and program characteristics against established models. Once completed, the visits and investigative evaluations should be made public, preferably on a Web site, allowing opportunity for the public to comment and to meet with the evaluators and funding/licensing agency staff.
- **Increase resident participation in inspections or evaluations.**—Each inspection or evaluation must include an opportunity for residents to meet with the investigators. Residents must be told what areas of the board and care home are being evaluated. They also must have an opportunity to recommend additional areas to be investigated that are either different aspects of the selected areas or new areas.
- **Identify other “mandatory reporters” for abuse and neglect concerns.**—These reporters should include all the advocacy groups in the community: independent living centers, drop-in centers for people who are homeless or have mental illness, local mental health associations, and so on. The reporters might also include doctors and health care workers.

### 7. Expand and Clarify the Mandate of Long-Term Care Ombudsman Program

- **Strengthen ombudsman programs.**—Ombudsman programs should pay closer attention to the needs of board and care residents, including transition to more integrated settings. These programs also should provide training on the rights of board and care residents and assist them in forming board and care residents' councils.
- **Encourage patients' rights advocates as well as ombudsman offices to work more closely with P&A agencies.**

## 8. Enhance Access to Physical and Mental Health Care

- **Ensure continuity of health care beyond residence.**—Adequate information, real choice of providers, and ability to continue under the care of specific providers are essential in order to ensure improved physical and mental health outcomes for board and care residents. The availability of health care should not depend on continued residence but be portable and continue beyond the time a person leaves a board and care home.
- **Guard against hospital patient “dumping.”**—Ensure that hospitals are not dumping patients in board and care homes that cannot meet their basic needs.
- **Develop wellness recovery action plans.**—Such recovery plans should be developed for every resident of a board and care home.
- **States should fund resident education and skill-building.**

## 9. Strengthen Residents’ Rights

- **Strengthen residents’ rights.**—State laws should require that board and care residents have the full rights of tenancy, including a lease, a key, and the right to privacy.
- **Develop bills of rights.**—Develop a template for a bill of rights for residents, specifying adequate due process with respect to eviction and quality-of-life issues. Ensure that the resulting bills of rights are enforceable through private lawsuits.
- **Prohibit seclusion and restraint.**—Prohibit the use of seclusion and restraint in board and care homes, both through State legislation and as a licensing requirement.

## 10. Establish Quality Improvement Measures

- **Provide quality mentoring programs.**—Ensure that reputable providers are available to mentor those who do not achieve high standards.
- **Offer training and technical assistance to providers.**—State oversight agencies should provide training and technical assistance to help providers meet minimum standards.
- **Develop incentives for best practices.**—Develop financial and other incentives for board and care homes to adopt best practices or other good policies.
- **Develop and enforce certification standards.**—Require initial and ongoing education and quality improvement plans as conditions for maintaining accreditation.





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# SECTION V

## CONCLUSION

In light of the Olmstead decision and the call by the President's New Freedom Commission to move public mental health to a recovery orientation, stranding people with mental health issues in board and care homes that isolate residents from the community is clearly not appropriate. Fully 15 years after the enactment of the ADA, this paper calls for concrete action by State and Federal governments toward ending reliance on needlessly segregated living arrangements such as board and care homes. Other recommendations are offered, not as an alternative to this recommended transformation, but as palliative measures to improve conditions for residents while this transformation is occurring.



# ENDNOTES

<sup>1</sup> The term “board and care home” describes living arrangements that provide shelter, food, and 24-hour supervision or protective oversight and personal care services to residents. Other terms for board and care homes include homes for the aged, residential care homes, adult foster care, domiciliary care and, recently, assisted living facilities. Such homes may be licensed or unlicensed, and range in size from 2 residents to more than 200.

<sup>2</sup> See, for example, U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality of Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm> (although there are a large number of small homes, the vast majority of board and care residents (52 percent of those in licensed homes and 84 percent in unlicensed homes) lived in large homes with more than 51 beds.)

<sup>3</sup> U.S. Department of Health and Human Services, *Licensed Board and Care Homes: Preliminary Findings From the 1991 National Health Provider Inventory* (April 11, 1994), available at <http://aspe.hhs.gov/daltcp/reports/licbchom.htm>.

<sup>4</sup> U.S. House of Representatives, Select Committee on Aging, *Board and Care Homes in America: A National Tragedy* (1989), Comm. Pub. 101-711. See also National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives* (August 19, 2003), available at <http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm> (800,000 people live in board and care homes).

<sup>5</sup> Lewin/ICF and James Bell Associates, *Descriptions of and Supplemental Information on Board and Care Homes Included in the Update of the National Health Provider Inventory* (August 8, 1990) (providing an unduplicated computerized listing of all potential licensed board and care (B&C) homes nationally, based on the National Center for Health Statistics' 1991 update of the National Health Provider Inventory).

<sup>6</sup> Nancy D. Dittmar, “Facility and Resident Characteristics of Board and Care Homes for the Elderly,” in *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute, 1989).

<sup>7</sup> Michael P. Accordino et al., “Deinstitutionalization of Persons with Severe Mental Illness: Context and Consequences,” *Journal of Rehabilitation* (April–June 2001), available at [http://articles.findarticles.com/p/articles/mi\\_m0825/is\\_2\\_67/ai\\_76398484](http://articles.findarticles.com/p/articles/mi_m0825/is_2_67/ai_76398484).

<sup>8</sup> See, for example, “A Brief History of Deinstitutionalization,” citing H.R. Lamb and V. Goertzel, “The Long-Term Patient in the Era of Community Treatment.” *Archives of General Psychiatry* 34, no. 6 (1977): 679–682.

<sup>9</sup> Ibid.

<sup>10</sup> See Accordino, note 7; “Brief History,” note 8.

<sup>11</sup> Clifford Levy, “Broken Home,” *New York Times*, April 28–30, 2002; Clifford J. Levy and Sarah Kershaw, “Inquiry Finds Mentally Ill Patients Endured ‘Assembly Line’ Surgery,” *New York Times*, March 18, 2001.

<sup>12</sup> David S. Fallis, “As Care Declines, Cost Can Be Injury, Death,” *Washington Post*, May 23, 2004; *ibid.*, “In Va.’s Assisted Living Homes, Violent Preyed on the Vulnerable,” *Washington Post*, May 24, 2004; *ibid.*, “Assisted Living Facility’s Chaos Bred Wide Neglect,” *Washington Post*, May 25, 2004; and *ibid.*, “Weak Laws Let Deficient Facilities Stay Open,” *Washington Post*, May 26, 2004.

<sup>13</sup> See Levy, *supra* note 11; Arline Kaplan, “Ensuring Appropriate Treatment for Patients,” *Psychiatric Times* XVIII, no. 9 (September 2001).

<sup>14</sup> Although fewer than .06 percent of respondents to a NAMI New Jersey survey preferred these homes as long-term housing settings, they had few other options. Testimony of Phillip Lubitz, NAMI New Jersey, to the New Jersey Assembly Regulatory Oversight Committee (September 30, 2002).

<sup>15</sup> U.S. Department of Health and Human Services, *Licensed Board and Care Homes: Preliminary Findings From the 1991 National Health Provider Inventory* (April 11, 1994), available at <http://aspe.hhs.gov/daltcp/reports/licbchom.htm>.

<sup>16</sup> U.S. House of Representatives, Select Committee on Aging, *Board and Care Homes in America: A National Tragedy* (1989). Comm. Pub. 101-711. See also National Council on Disability, *Olmstead: Reclaiming Institutionalized Lives* (August 19, 2003), available at <http://www.ncd.gov/newsroom/publications/2003/reclaimlives.htm> (800,000 people live in board and care homes).

<sup>17</sup> Lewin/ICF and James Bell Associates, *Descriptions of and Supplemental Information on Board and Care Homes Included in the Update of the National Health Provider Inventory* (August 8, 1990) (providing an unduplicated computerized listing of all potential licensed board and care (B&C) homes nationally, based on the National Center for Health Statistics’ 1991 update of the National Health Provider Inventory).

<sup>18</sup> Nancy D. Dittmar, “Facility and Resident Characteristics of Board and Care Homes for the Elderly,” in *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute, 1989).

<sup>19</sup> AARP Public Policy Institute, “Board and Care Homes,” Fact Sheet 23 (April 1993). See also Nancy D. Dittmar, “Facility and Resident Characteristics of Board and Care Homes for the Elderly,” in *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute, 1989), 2. Typically, a board and care home refers to nonmedical, community-based residential settings that house two or more unrelated adults and provide such services as meals, medication supervision or reminders, organized

activities, transportation, or help with activities of daily living. U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality and Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>. Although a new industry, calling itself “assisted living,” has sprung up over the past two decades, the “most common type of assisted living facility cannot be easily distinguished from traditional board and care homes. A significant proportion of resident rooms were shared rather than private, and such facilities offered little beyond assistance with medications, bathing, or dressing. In about half the ALFs described by this model, there was at least one room shared by three or more people. This model, which we define as minimal or low service/low privacy, represented 58 percent of all the places that described themselves as assisted living.” Catherine Hawes, Senior Research Scientist, Myers Research Institute, Menorah Park Center for the Aging, Cleveland, Ohio. Testimony to Senate Committee on Aging (2000).

<sup>20</sup> See, for example, L.A. Morgan et al., *Small Board-and-Care Homes: Residential Care in Transition* (Baltimore: Johns Hopkins University Press, July 1995) (analyzing economic and care considerations in such settings); L.A. Morgan et al., “Social Marginality: The Case of Small Board and Care Homes,” *Journal of Aging Studies* 7, no. 4 (1993): 383–394. See also Levy, note 11.

<sup>21</sup> U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality and Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>.

<sup>22</sup> AARP Public Policy Institute, “Board and Care Homes,” Fact Sheet 23 (April 1993).

<sup>23</sup> J.K. Eckert and S.M. Lyon, “Regulation of Board and Care Homes: Research to Guide Policy,” *Journal of Aging and Social Policy* 3 (1991): 147–162.

<sup>24</sup> Section 1616(e) of the Social Security Act, 42 U.S.C. §1382e.

<sup>25</sup> Some States prohibit licensed board and care facilities from serving as representative payees of SSI or SSDI benefits. See GN 00502.163, Additional Development/Considerations (“When Board and Care/Room and Board Facility Involved. Section 1616(e) of the Act (also known as the Keys Amendment) requires that States create or designate one or more agencies to establish, maintain, and ensure enforcement of standards for group living facilities. Each State agency is required to prepare and issue lists of noncomplying facilities to SSA regional offices on an ongoing basis. When a board and care facility is being considered as a payee, check the State listings. In the absence of a State listing, assume that the State has found all facilities to be in compliance. If you find that the facility is not in compliance with state laws, consider an alternate payee. If there is any doubt about whether or not a facility is in compliance, initiate direct contact with the State for verification.”)

<sup>26</sup> See, for example, Nancy D. Dittmar, “Facility and Resident Characteristics of Board and Care Homes for the Elderly,” in *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute, 1989).

<sup>27</sup> 28 C.F.R. § 130(d). See also Bazelon Center for Mental Health Law, “Lawsuit Seeks Community Integration of Thousands of New Yorkers with Mental Illnesses,” press release, July 1, 2003, available at [http://www.bazelon.org/newsroom/7103ny\\_pressrelease.htm](http://www.bazelon.org/newsroom/7103ny_pressrelease.htm) (describing *Disability Advocates Inc. v. Pataki* (E.D.N.Y. filed July 1, 2003), on behalf of approximately 4,000 individuals with serious mental illnesses who reside in large adult homes in New York City. The lawsuit alleges that New York State is violating Federal laws, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act, by unlawfully segregating individuals).

<sup>28</sup> See, generally, *The NIMBY Report*, available at <http://www.nlihc.org/nimby>. See also National Low Income Housing Coalition, “The Olmstead Factor: Integrating Housing for People with Disabilities,” *The NIMBY Report* (Spring 2002), available at <http://www.nlihc.org/nimby/index.htm>.

<sup>29</sup> Arlene S. Kanter, “A Home of One’s Own: The Fair Housing Amendments Act of 1988 and Housing Discrimination Against People with Mental Disabilities,” 43 AM. U. L. REV. 925, 993 (1994), citing Nancy K. Rhoden, “The Limits of Liberty: Deinstitutionalization, Homelessness, and Libertarian Theory,” 31 EMORY L.J. 375, 388 (1982).

<sup>30</sup> See, for example, Consortium for Citizens with Disabilities Housing Task Force and Technical Assistance Collaborative, Inc., *Opening Doors: Recommendations For A Federal Policy To Address The Needs Of People With Disabilities* (September 1996); see also National Action Coalition For Disability Rights In Housing, Responding To HUD’s “Housing For Persons With Disabilities”: Debunking The Myths And Recommending Policies We Can Live With (January 1995)..

<sup>31</sup> Consortium for Citizens With Disabilities, *supra* note 30, at 8. “[T]he already acute housing crisis faced by people with disabilities became even more severe with the enactment of Title VI of the Housing and Community Development Act of 1992 (P.L. 102-550). Another blow came with passage of Section 10 of the Housing Opportunity Extension Act of 1996 (P.L. 104-20). With the enactment of this legislation, hundreds of thousands of HUD public and assisted housing units previously available to people with disabilities have been and will increasingly be designated exclusively for elderly households.” See also Diane Engster, Henry Korman, and Bonnie Milstein, “Housing as a Tool of Coercion,” in *Coercion and Aggressive Community Treatment: A New Frontier in Mental Health Law*, ed. Deborah L. Dennis and John Monahan (New York: Plenum Publishing Corporation, 1996).

<sup>32</sup> See Paul J. Carling, “Housing and Supports for Persons with Mental Illness: Emerging Approaches to Research and Practice,” *Hospital and Community Psychiatry* 44 (May 1993): 439, 440. (“Historically, mental health agencies have viewed housing as a social welfare problem and

have defined their role exclusively in terms of treatment. Public housing agencies, in turn, have contended that consumers need specialized residential programs and have viewed housing needs as a responsibility of mental health agencies. Thus, housing needs have often been ignored.”)

<sup>33</sup> See, for example, *Task Force On Homelessness And Severe Mental Illness, Outcasts On Main Street* (1992); see also U.S. Department of Housing and Urban Development, *Priority Home!: The Federal Plan to Break the Cycle of Homelessness* (May 1994), HUD-1454-CPD.

<sup>34</sup> Paul J. Carling, “Housing and Supports for Persons with Mental Illness: Emerging Approaches to Research and Practice,” *Hospital and Community Psychiatry* 44 (May 1993): 439, 441 (noting that many individuals remain in psychiatric hospitals because of the lack of housing, or cycle through emergency rooms and general hospitals in costly and often inappropriate stays).

<sup>35</sup> This outcome is not surprising, given the economic forces at work. When people with psychiatric or other disabilities are admitted to publicly operated institutions, like psychiatric hospitals or jails and prisons, Social Security regulations require that their SSI and SSDI benefits be suspended or terminated. By regulation and practice, people living in board and care homes get to keep their disability checks and use them toward room and board, thereby decreasing the amount of subsidy the State is required to pay. Privately owned board and care homes often agree to become the representative payee, and to take a resident’s entire SSI or SSDI check and a State supplement, returning only a small personal needs allowance to residents.

<sup>36</sup> See, for example, R.A. Dorwart and M. Schlesinger, “Privatization of Psychiatric Services,” *American Journal of Psychiatry* 145 (1998): 543–553.

<sup>37</sup> *Mental Health: A Report of the Surgeon General* (1999), available at <http://www.surgeongeneral.gov/library/mentalhealth/home.html>, at 293, citing P. Polak and R. Warner, “The Economic Life of Seriously Mentally Ill People in the Community,” *Psychiatric Services* 47 (1996): 270–274.

<sup>38</sup> *Ibid.*, citing C.I. Cohen, “Poverty and the Course of Schizophrenia: Implications for Research and Policy,” *Hospital and Community Psychiatry* 44 (1993): 951–958; B. Saraceno and C. Barbui, “Poverty and Mental Illness,” *Canadian Journal of Psychiatry* 42 (1997): 285–290.

<sup>39</sup> B.C. Ho, N. Andreasen, and M. Flaum, “Dependence on Public Financial Support Early in the Course of Schizophrenia,” *Psychiatric Services* 48 (1997): 948–950.

<sup>40</sup> National Institute on Disability and Rehabilitation Research, *Strategies to Secure and Maintain Employment for People with Long-term Mental Illness* (1992).

<sup>41</sup> See U.S. Census Bureau, *Disability* (January 2001), available at [http://www.census.gov/population/www/pop\\_profile/disabil.html](http://www.census.gov/population/www/pop_profile/disabil.html).

<sup>42</sup> See, generally, “SSI State Supplements - Overview,” available at [http://www.workworld.org/wwwwebhelp/ssi\\_state\\_supplements\\_overview.htm](http://www.workworld.org/wwwwebhelp/ssi_state_supplements_overview.htm). The States not offering such supplements are Arkansas, Georgia, Kansas, Mississippi, Tennessee, and West Virginia.

<sup>43</sup> Technical Assistance Collaborative, Inc., and Consortium for Citizens with Disabilities, *Priced Out in 2002*, available at <http://www.tacinc.org/Docs/HH/PricedOutIn2002.pdf>. (“Of the nation’s 2,702 market areas, there was not a single area where modestly priced rents for efficiency or one-bedroom units were affordable for people with disabilities receiving SSI.”)

<sup>44</sup> 42 U.S.C. §1396d(i).

<sup>45</sup> Technical Assistance Collaborative, Inc., and Consortium for Citizens with Disabilities, *Priced Out in 2002*, available at <http://www.tacinc.org/Docs/HH/PricedOutIn2002.pdf>.

<sup>46</sup> National Long Term Care Ombudsman Resource Center, *Personal Needs Allowance for Long Term Care Residents* (December 2001).

<sup>47</sup> Alexander Chen, “The Cost of Operation in Board and Care Homes,” in *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute), 1989.

<sup>48</sup> See Timothy M. Cook, “The Americans with Disabilities Act: The Move to Integration,” 64 Temp. L. Rev. 393, 401 (1991) (noting that people with severe disabilities were considered, in the view of one State agency, “a defect...[that] wounds our citizenry a thousand times more than any plague.” See also *City of Cleburne v. Cleburne Living Center*, 473 U.S. 423, 460–463 (1985) (J. Marshall, concurring in part and dissenting in part) (noting that, as a result of Social Darwinism and other forces that led many experts to consider people with mental disabilities as menaces to society, “[a] regime of state-mandated segregation and degradation soon emerged that in its virulence and bigotry rivaled, and indeed paralleled, the worst excesses of Jim Crow.”)

<sup>49</sup> One rather typical restriction imposed by public housing authorities (PHAs) was the requirement that people with disabilities demonstrate that they were “capable of independent living.” As that policy was implemented in Rochester, New York, for example, it disqualified people who relied on personal care attendants, visiting nurses, and chore aides from living in public housing. This policy was not struck down until 1990, when advocates brought suit under the Rehabilitation Act and the Fair Housing Act. See *Cason v. Rochester Housing Authority*, 748 F.Supp. 1002 (W.D.N.Y. 1990). Another, more recent, example is Federal legislation in 1992 that permits PHAs and private owners of subsidized housing to designate certain buildings as “elderly only,” and exclude people with disabilities. See “What’s Wrong With This Picture? An Update on the Impact of Elderly Only Housing Policies on People with Disabilities,” *Opening Doors* 15 (September 2001), available at <http://www.c-c-d.org/Issue15.pdf>.



<sup>50</sup> See “The States’ Response to The Olmstead Decision: A Work in Progress,” published by the National Conference of State Legislatures in January 2002. Full text of the report is available at <http://www.ncsl.org/programs/health/forum/olmsreport.htm#findingsbot>.

<sup>51</sup> See “Delivering on the Promise: Preliminary Report of Federal Agencies’ Actions to Eliminate Barriers and Promote Community Integration,” presented to the President of the United States, December 21, 2001, available at <http://www.hhs.gov/newfreedom/prelim/>.

<sup>52</sup> President’s New Freedom Commission on Mental Health, *Interim Report to the President* (October 29, 2002), available at <http://www.mentalhealthcommission.gov/reports/reports.htm>.

<sup>53</sup> President’s New Freedom Commission on Mental Health, *Interim Report to the President* (October 29, 2002), available at <http://www.mentalhealthcommission.gov/reports/reports.htm>.

<sup>54</sup> See U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality and Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>; Lewin/ICF and James Bell Associates, *Descriptions and Supplemental Information on Board and Care Homes Included in the Update of the National Health Provider Inventory*, Contract No. HHS-100-86-0051 (Washington, D.C.: Lewin/ICF, 1990); John L. McCoy and Ronald W. Conley, “Surveying Board and Care Homes: Issues and Data Collection Problems,” *The Gerontologist* 30 no. 2 (1990): 147–153; *Preserving Independence, Supporting Needs: The Role of Board and Care Homes* (Washington, D.C.: AARP Public Policy Institute), 1989.

<sup>55</sup> See, for example, State of West Virginia Office of Legislative Auditor, *Sunrise Report on the Licensing of Assisted Living Administrators* (August 2001) (concluding “there is a potential for harm to residents of assisted living facilities that warrants regulation”); Report of the Office of the Dixon Special Master, *District of Columbia Adult Mental Health System: A Review of Contractor Residential Services* (January 1997); *The State Mental Health Redirection Plan, Two Years Later: A Retrospective and Status Report* (2000), available at <http://www.state.nj.us/humanservices/dmhs/retrospective.html>; New York State Commission on Quality of Care for the Mentally Disabled, *Adult Homes Serving Residents with Mental Illness: A Study of Conditions, Services and Regulation* (October 1990); New York State Commission on Quality of Care for the Mentally Disabled, *Adult Homes Serving Residents with Mental Illness: A Study on Layering of Services* (August 2002); Maryland Office of Planning/Domiciliary Care Facilities Board, *Regulated Board and Care Facilities in Maryland* (February 1994); and Collaborative Support Programs of New Jersey, *1996 Boarding Home Resident Survey for Monmouth and Ocean Counties* (April 1996).

<sup>56</sup> See Levy and Fallis, *supra* notes 11 and 12.

<sup>57</sup> New York, for instance, has experienced at least three waves of crisis-oriented reform, beginning in 1977 when the State released the report *Private Proprietary Home for Adults* and enacted a law requiring joint visitation by the Office of Mental Health and the Department of Social Services. In 1979, the New York State Department of Social Services commissioned a report on characteristics of adult home residents and developed a plan of action to address problems identified by the report. Thereafter, in 1990, the State's Commission on Quality Care for the Mentally Disabled issued the report *Adult Homes Service Resident with Mental Illness*, at the request of the New York State Legislature. In partial response, New York State implemented the Quality Incentive Payment Program in 1996 to improve the physical plant in adult homes. In 2000, a workgroup convened by the State Communities Aid Association in New York released its report, *There's No Place Like Home: Recommendations for Improving the Quality of Life in Adult Homes Serving People with Mental Illness*. Less than 2 years later, the New York Times chronicled pervasive problems in adult homes, and the cycle of crisis response continued, with the appointment of the New York State Adult Care Facilities Workgroup.

<sup>58</sup> U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality and Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>.

<sup>59</sup> Ibid.

<sup>60</sup> U.S. Department of Health and Human Services, *Licensed Board and Care Homes: Preliminary Findings From the 1991 National Health Provider Inventory* (April 1994).

<sup>61</sup> See also American Association for Retired Persons, *The Board and Care System: A Regulatory Jungle* (Washington, D.C.: American Association of Retired Persons); C. Hawes et al., *The Regulation of Board and Care Homes: Results of a Survey in the 50 States and the District of Columbia* (Washington, D.C.: American Association of Retired Persons, 1993); Lewin/ICF and James Bell Associates, *Descriptions and Supplemental Information on Board and Care Homes Included in the Update of the National Health Provider Inventory*, Contract No. HHS-100-86-0051 (Washington, D.C.: Lewin/ICF, 1990); John L. McCoy and Ronald W. Conley, "Surveying Board and Care Homes: Issues and Data Collection Problems," *The Gerontologist* 30, no. 2 (1990): 147-153; Mary Naifeh and William Downs, *Searching for a Needle in a Haystack: Creative Use of the Decennial Census Dress Rehearsal Data to Find Board and Care Places in Central Missouri* (Washington, D.C.: U.S. Department of Health and Human Services/Office of the Assistant Secretary for Planning and Evaluation, 1992); Al Sirocco, "Nursing Home and Board and Care Homes," *Advance Data from Vital and Health Statistics*, No. 244, Hyattsville, Md.: National Center for Health Statistics, 1994); U.S. Department of Health and Human Services, Office of the Inspector General, *Board and Care*, Report No. OEI-02-89-01860 (Washington, D.C.: Office of the Inspector General, 1990); U.S. General Accounting Office, *Board and Care: Insufficient Assurances that Residents' Needs*

are Being Met, Report No. GAO/HRD-89-50 (Washington, D.C.: General Accounting Office, 1989); and U.S. House of Representatives, Select Committee on Aging, *Board and Care Homes in America: A National Tragedy*, Comm. Pub.101-711 (Washington, D.C.: U.S. Government Printing Office, 1989).

<sup>62</sup> U.S. Department of Health and Human Services, *Licensed Board and Care Homes: Preliminary Findings From the 1991 National Health Provider Inventory* (April 1994).

<sup>63</sup> Testimony of Phillip Lubitz, Coordinator of Family Support and Advocacy Programs, NAMI of New Jersey, before the September 30, 2002 meeting of the New Jersey Assembly Regulatory Oversight Committee concerning the management and operation of nursing conditions, and the role of the State government in ensuring the well-being of residents. Accessed at <http://www.njleg.state.nj.us/legislativepub/Pubhear/093002RS.htm>

<sup>64</sup> In New Jersey, for instance, the State estimates that more than 9,000 individuals with mental illnesses live in board and care homes that can meet the regulatory “level of care” requirements by providing as little as 12 minutes of nursing care a week. Testimony of Phillip Lubitz, NAMI New Jersey, to the New Jersey Assembly Regulatory Oversight Committee (September 30, 2002).

<sup>65</sup> See supra note 45.

<sup>66</sup> Sandra Hughes and Gail MacInnes, *Personal Needs Allowance For Long Term Care Residents* (National Long Term Care Ombudsman Resource Center, December 2004), available at <http://www.ltombudsman.org/uploads/PNAforLTCResidents.pdf>.

<sup>67</sup> Ibid.

<sup>68</sup> E.D. Edmunson et al., “Integrating Skill Building and Peer Support in Mental Health Treatment: The Early Intervention and Community Network Development Projects,” in *Community Mental Health and Behavioral Ecology*, ed. A.M. Jeger and R.S. Slotnick (New York: Plenum Press, 1982), 127–139; M. Galanter, “Zealous Self-Help Groups as Adjuncts to Psychiatric Treatment: A Study of Recovery, Inc.,” *American Journal of Psychiatry*, 145, no. 10 (1988): 1248–1253.

<sup>69</sup> E-mail communication to author from Thomas L. Wood, Chief, Office of Licensure and Certification, Ohio Department of Mental Health, March 30, 2005.

<sup>70</sup> *The State Mental Health Redirection Plan, Two Years Later: A Retrospective and Status Report* (2000), available at <http://www.state.nj.us/humanservices/dmhs/retrospective.html>.

<sup>71</sup> See Peer Bridger Program Mission at [http://www.nyaprs.org/pages/view\\_content\\_A.cfm?ContentID=47](http://www.nyaprs.org/pages/view_content_A.cfm?ContentID=47).

<sup>72</sup> The 2002 NYS Adult Care Facilities Workgroup Report comprises eight appendices: (1) A: Adult Care Facility Workgroup; (2) B: Housing Options; (3) C: Presentations to New Models Workgroups; (4) D:

Supportive Congregate Housing as an Alternative to Adult Homes; E: Office of Mental Health Residential Programs Typology; F: Capital Financing, Housing Subsidy, and Service Programs Available for Affordable Senior Housing; G: SSI Benefit Levels Chart; and H: New York State Commission on Adult Homes. See [http://www.scaany.org/docs/workgrp\\_appendicesA-DH.pdf](http://www.scaany.org/docs/workgrp_appendicesA-DH.pdf).

<sup>73</sup> Conn. Gen. Stat. §17a-484b.

<sup>74</sup> 42 U.S.C. 10801 et seq.

<sup>75</sup> 42 U.S.C. §10802(4)(B)(ii).

<sup>76</sup> A personal care boarding home is “a residential facility that makes available to three or more adults not related to the owner of such facility, either directly or indirectly through a provider agreement, room and board and personal services, protective oversight, and social care due to impaired capacity to live independently, but not to the extent that regular 24-hour medical or nursing care is required.”

<sup>77</sup> U.S. Department of Health and Human Services, *Report on the Effects of Regulation on Quality and Care: Analysis of the Effect of Regulation on the Quality of Care in Board and Care Homes* (December 1995), available at <http://aspe.hhs.gov/daltcp/reports/b&crpt.htm>.

<sup>78</sup> American Bar Association, Commission on Legal Problems of the Elderly and Commission on the Mentally Disabled, “A Model Act Regulating Board and Care Homes: Guidelines for States,” *Mental And Physical Disability Law Reporter* 8 (March–April 1984): 150; Michael Schuster, “Board and Care; How Effective Are Licensing Standards?” *Clearinghouse Review*, Oct. 1993, at 600, 605 (stating that the most at-risk elderly and disabled adults live in board and care homes); *ibid.* at 604 (indicating that 28,000 board and care homes are unlicensed); *ibid.* at 600 (defining board and care as nonmedical community-based living arrangements that provide shelter, board, 24-hour supervision or protective oversight, and personal care services to residents (not related to the operator)) (quoting C. Hawes et al., *The Regulation of Board and Care Homes: The Result of a Survey in the 50 States and The District of Columbia* (Washington, D.C.: American Association of Retired Persons, 1993): 3.

<sup>79</sup> AARP Public Policy Institute, *Adult Foster Care for the Elderly: A Review of State Regulatory and Funding Strategies* (March 1996); Vincent Mor, *Community Connections In Board And Care Homes Serving Chronically Ill Adults In Ten States, 1993-1994* [computer file]. Inter-university Consortium for Political and Social Research (ICPSR) version. Providence, RI: Brown University [producer], 1996. Ann Arbor, MI: ICPSR [distributor], 1996. Date updated: October 8, 1996.

<sup>80</sup> “Board and Care Homes Vary in Services Offered, Need Stricter Regulation,” a Web summary of research by the Brown University Center for Gerontology and Health Care Research, from the Robert Wood Johnson Foundation Web site, available at [http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=016772s.htm&iaid=144#int\\_grantinfo](http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=016772s.htm&iaid=144#int_grantinfo).

<sup>81</sup> 42 U.S.C. §3058g.

<sup>82</sup> The Older Americans Act at 42 U.S.C. §3058g(h)(6) requires each State long-term-care ombudsman agency to “coordinate ombudsman services with the protection and advocacy systems” for people with developmental disabilities and mental illnesses established under the Developmental Disabilities Assistance and Bill of Rights Act of 2000 and the Protection and Advocacy for Mentally Ill Individuals Act of 1986.

<sup>83</sup> See Atlanta Legal Aid, *Choosing a Personal Care Home*, available at <http://www.atlantalegalaid.org/fact24.htm>.

<sup>84</sup> See the “Facility Location and Information Guide,” available at <http://www.ors.dhr.state.ga.us/>.

<sup>85</sup> Kan. Stat. Ann. §75-7301 (2000).

<sup>86</sup> Kan. Stat. Ann. §75-7306 (2000).

<sup>87</sup> La. Rev. Stat. Ann. §40:2010.3 (2000).

<sup>88</sup> Wash. Rev. Code §43.190.030 (2001).

<sup>89</sup> Administration on Aging, U.S. Department of Health and Human Services, *Long-Term Care Ombudsman Report, FY 2001*, available at [http://www.aoa.gov/prof/aoaprogram/elder\\_rights/LTCombudsman/National\\_and\\_State\\_Data/2001nors/2001OMBDS%20Reportfinal.pdf](http://www.aoa.gov/prof/aoaprogram/elder_rights/LTCombudsman/National_and_State_Data/2001nors/2001OMBDS%20Reportfinal.pdf). The data do not reflect the number of complaints from people with psychiatric disabilities residing in board and care homes.

<sup>90</sup> Section 202 (a)(21)(A-B) of the Older Americans Act.

<sup>91</sup> National Long Term Care Ombudsman Resource Center, *Ombudsmen Comprehensive Curriculum Manual*, available at [http://www.ltcombudsman.org/ombpublic/49\\_506\\_1789.cfm](http://www.ltcombudsman.org/ombpublic/49_506_1789.cfm).

<sup>92</sup> “Board and Care Homes Vary in Services Offered, Need Stricter Regulation,” a Web summary of research by the Brown University Center for Gerontology and Health Care Research, from the Robert Wood Johnson Foundation Web site, available at [http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=016772s.htm&iad=144#int\\_grantinfo](http://www.rwjf.org/portfolios/resources/grantsreport.jsp?filename=016772s.htm&iad=144#int_grantinfo).

<sup>93</sup> See Friends of Residents in Long Term Care, *Residents’ Rights while Living in an Adult Care Home*, available at <http://www.forltc.org/achbillrights.html>.

<sup>94</sup> Minn. Stat. §144.651.

<sup>95</sup> South Dakota Department of Health, Administrative Rules Chapter 44:04:17.

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<sup>97</sup> Valorie Williams, “Resident Autonomy in the Board and Care Setting,” 6(3) Board & Care Quality Forum, 6, no. 3 (May-June 2003): 1.

<sup>98</sup> Robynn M. Pease, Ph.D., M.A., “Slighted Care: The Marginalization of Kentucky’s Board and Care Homes,” *Board & Care Quality Forum*, 5, no. 6 (November-December 2002): 1.

<sup>99</sup> Deborah Nebel, J.D. and Lida Mackey, “Best Practice Standards and Legal and Ethical Principles of Confidentiality in Board and Care Homes,” *Board & Care Quality Forum*, 5, no. 2 (March-April 2002): 1.

<sup>100</sup> “One Woman’s Journey with Residence and Recovery: An Interview with Kamala Castle,” *Board & Care Quality Forum*, 4, no. 5 (September-October 2001): 1.

<sup>101</sup> See, for example, K.H. Namazi et al., “Psychological Well-Being of Elderly Board and Care Home Residents,” *The Gerontologist* 29, no. 4 (1989): 511–516.

<sup>102</sup> New York State Coalition for Adult Home Reform, NYSCAHR *Budget Recommendations* (2004), available at [http://www.scaany.org/collaborations/documents/nyscahr\\_budgetrec\\_04\\_000.pdf](http://www.scaany.org/collaborations/documents/nyscahr_budgetrec_04_000.pdf).

<sup>103</sup> Sam Tsemberis and Ronda Eisenberg, “Pathways to Housing: Supported Housing for Street-Dwelling Homeless Individuals With Psychiatric Disabilities,” *Psychiatric Services* 51 (2000): 487–493.

<sup>104</sup> *Ibid.* at 489.

<sup>105</sup> *Ibid.* at 491. See also James M. Mandelberg and Lawrence Telles, “The Santa Clara County Clustered Apartment Project,” *Journal of Psychiatric Rehabilitation*, 14 (1990): 21 (even people with severe impairments can succeed in the right housing model; also deals with issues of social isolation by establishing scattered site housing in a small geographic area where people can walk to see one another, and where consumers are actively encouraged to provide social support for one another).

<sup>106</sup> Tsemberis and Eisenberg, *supra* note 102, at 492.

<sup>107</sup> In September 1999, the California legislature enacted AB 34 to provide funding for three counties (Los Angeles, Sacramento, and Stanislaus) for Demonstration Pilot programs to provide comprehensive services to severely mentally ill persons who are “homeless recently released from a County jail or the State prison, or others who are untreated, unstable, and at significant risk of incarceration or homelessness unless treatment is provided to them.” Since that time, the California Department of Mental Health estimates that people served by AB 34 programs have experienced a 66-percent decrease in the number of days of psychiatric hospitalization, an 82-percent decrease in days of incarceration, and 80 percent fewer days of homelessness. See President’s New Freedom Commission on Mental Health, *Interim Report to the President*, at Box 4.

<sup>108</sup> See Clifford Levy, “For Mentally Ill, Death and Misery,” *New York Times*, April 28, 2002, at A1. Eyal Press and Jennifer Washburn, “Neglect for Sale,” *American Prospect*, 11, no. 12, May 8, 2000; Katherine Boo, “Invisible Deaths: The Fatal Neglect of D.C.’s Retarded: System Loses Lives and Trust,” *Washington Post*, December 5, 1999, at A1.

<sup>109</sup> See Beth Tanzman, “An Overview of Surveys of Mental Health Consumers’ Preferences for Housing and Support Services,” *Hospital and Community Psychiatry* 44 (1993): 450. See also E. Sally Rogers et al., “The Residential Needs and Preferences of Persons with Serious Mental Illness: A Comparison of Consumers and Family Members,” *Journal of Mental Health Administration* 21, no. 1 (1994): 42. See Schutt and Goldfinger, *supra* note 34, at 382 (citing Paul Carling, “Major Mental Illness, Housing, and Supports: The Promise of Community Integration,” *American Psychologist* 45 (1990): 969–975. (“The belief that consumer choice should be a central principle of housing placement is based on the philosophy that persons who are mentally ill have the right to make their own decisions and the belief that these persons will make appropriate choices about the supports they need.”) Russell K. Schutt and Stephen M. Goldfinger, “Housing Preferences and Perceptions of Health and Functioning Among Homeless Mentally Ill Persons,” *Psychiatric Services* 47 (1996): 381–386 (diagnosis of mental illness does not interfere with rational decisionmaking about where to live).

<sup>110</sup> Testimony of Phillip Lubitz, NAMI New Jersey, to the New Jersey Assembly Regulatory Oversight Committee (September 30, 2002).

<sup>111</sup> See, for example, Geoffrey Nelson, G. Brent Hall, and Richard Walsh-Bowers, “A Comparative Evaluation of Supportive Apartments, Group Homes, and Board-and-Care Homes for Psychiatric Consumer/Survivors,” *Journal of Community Psychology* 25 (1997): 167–188; Susan Burek, et al., *Third-Year Outcomes of Supported Housing in Texas: Measuring the Long-Term Effects of System Change* (Texas Department of Mental Health and Mental Retardation, February 1996); and P. Ridgway and P. Carling, *Meeting the Supported Housing and Residential Services Needs of Americans with Psychiatric Disabilities* (Boston: Center for Psychiatric Rehabilitation, 1986).

<sup>112</sup> F. Baker and C. Douglas, “Housing Environments and Community Adjustment of Severely Mentally Ill Persons,” *Journal of Community Mental Health* 26, no. 6 (1990): 497–505.

<sup>113</sup> Debra J. Rog and John Hornik, “Research to Practice: Implications of a National Study of Supported Housing” (Paper presented at the Institute of State Olmstead Coordinators, October 2, 2002) (on file with author) (Although consumers in supportive housing programs tended to receive fewer mental health and housing-related services than consumers living in group homes and supervised apartments, they show no significant differences in outcomes). J. McCarthy & G. Nelson, “An Evaluation of Supportive Housing for Current and Former Psychiatric Patients,” *Hospital and Community Psychiatry* 42, no. 12 (1991): 1254–1256.

<sup>114</sup> Debra Srebnik et al., “Housing Choice and Community Success for Individuals with Serious and Persistent Mental Illness,” *Journal of Community Mental Health* 31, no. 2 (1995): 139–152.

<sup>115</sup> Priscilla Ridgeway and Anthony M. Zipple, “The Paradigm Shift in Residential Services: From the Linear Continuum to Supported Housing Approaches,” *Journal of Psychosocial Rehabilitation* 13, no. 4 (1990): 11.

<sup>116</sup> See Ann O'Hara and Stephen Day, *Olmstead and Supportive Housing: A Vision for the Future* (Lawrenceville, N.J.: Center for Health Care Strategies, December 2001).



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