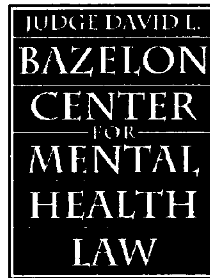

Just Like Where You and I Live

Integrated Housing Options for People with Mental Illnesses

By Michael Allen
Staff Attorney
Judge David L. Bazelon Center for Mental Health Law
1101 15th Street, NW, Suite 1212
Washington, DC 20005
202-467-5730
202-223-0409
Website: www.bazelon.org

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by Michael Allen[1]

Community integration stands in stark contrast to outdated views of people with psychiatric disabilities—whether held by professionals, family members, or the general public—as perennial patients, helpless and dependent, with hopeless futures....These outmoded beliefs about people with psychiatric disabilities...will die hard in the mental health field.[2]

INTRODUCTION

More than a decade after Carling observed a "paradigm shift" in thinking about full community participation by and integration of people with psychiatric disabilities,[3] the idea that mental health professionals should use housing as leverage to induce consumers to comply with mental health treatment plans seems oddly out of step. More than two decades ago, Test and Stein warned that "special living arrangements" should be avoided,[4] in large part because such arrangements stigmatize mental illnesses and make recovery and integration even more difficult.

If we believe that housing is an integral part of community integration, then we should resist the kind of housing models that segregate people by psychiatric diagnosis and communicate to the world that the residents are different. If the objective is successful community integration, then housing for people with psychiatric disabilities should look like where you and I live.[5]

A PARADIGM SHIFT

With respect to housing, the paradigm shift involves a fundamental redefinition of the relationship between consumers and housing and service providers.[6] While group homes and other congregate models that "bundled" housing and services may have been cutting-edge technology in the 1970s, they

have become dinosaurs, just like the state hospitals before them. A number of commentators have suggested that such housing is on precarious legal footing.[7] A growing number of other mental health stakeholders, including mental health commissioners,[8] advocacy organizations,[9] providers[10] and federal government agencies,[11] have made it clear that such coercive housing practices no longer have a place in the mental health system. They suggest that the principles of person-centered planning and choice must prevail over administrative convenience and familiar modes of administration.[12]

The central question is not what policies will promote compliance with mental health treatment, but rather, what role stable, integrated, unbundled housing can play in securing good life outcomes.[13] As part of that discussion, we must make clear that people with psychiatric disabilities may need and want supportive services, and that such service linkages may be critical in helping them to succeed in the community.[14] Although there may be a fine line between linking and bundling, that line is defined in terms of voluntariness.[15]

"SPECIALIZED" HOUSING STIGMATIZES PEOPLE WITH MENTAL ILLNESSES

In the mainstream housing market, tenants are required to comply with the core responsibilities of tenancy. These usually include paying the rent, complying with the lease, living at peace with neighbors and keeping the rental property in good condition

But most tenants with psychiatric disabilities are too poor to afford housing at market rates,[16] and many operators of public and subsidized housing are unwilling to rent to them.[17] As a consequence, state and local mental health agencies began to develop their own housing programs, even though many had little or no experience in the housing field.[18] Because mental health systems developed models to combine housing and services in a single setting, such programs were "typically segregated, professionally staffed, and congregate in nature..."[19] Given that consumers had received the entire bundle of housing and mental health services almost exclusively in hospital settings, it is not surprising that "what developed were residential programs, located in the community, that simply replicated institutional programs."[20]

Living in the community implies the room to make one's own decisions (and mistakes), and to learn from the experience.[21] The use of housing programs that shield consumers and mental health systems from the consequences of such freedom of choice undermines the very premise of community integration.[22] Most mental health agencies acknowledge the centrality of choice and self-determination to the process of recovery. Even with this guiding philosophy, though, the range of choice is often constrained to choices deemed acceptable by

the agencies themselves.[23]

Many states still take the view that people with disabilities (or people who are homeless) need "beds" or "slots" rather than homes. In this view, every person served represents an income stream that can help to support the operation of a group home, shelter or other congregate facility. This view is shared by many state and private agencies who feel they have a substantial stake in maintaining the current system of contracting and procurement, and thereby supporting their financial investments in congregate facilities. When people with disabilities are reduced to commodities in this fashion, community integration and responding to individual needs are not the primary objectives; rather, supposed efficiencies in the delivery of mental health services and preservation of the status quo are paramount.

Consumers find themselves in a precarious position because of the "bundling" of housing and services, with the attendant requirement that they comply with a treatment program in order to retain their housing. The inherent coercion involved in such an approach leaves consumers with little voice in their recovery plans. In other words, they do not aggressively question the treatment program prescribed for them because they fear they will put their housing in jeopardy. Similarly, overly restrictive rules (such as curfews), written for providers' convenience, often prevent consumers from taking an active role in community affairs.

People with psychiatric disabilities generally want the same kinds of housing that other citizens want.[24] They want a range of housing options, and many express a preference to live on their own and not be grouped with other people on the basis of mental health service needs. They also prefer housing without high levels of behavioral demand, and that preference appears to be unrelated to diagnosis or severity thereof.[25] In short, they want housing that is not identifiable as "mental health housing." Obviously, there is some risk in considering only consumer housing preferences,[26] but failure to give them appropriate weight may also lead to disappointing outcomes.[27]

OLMSTEAD PLACES LIMITATIONS ON "MENTAL HEALTH" HOUSING

In addition to the therapeutic and ethical reasons to disfavor the use of housing as leverage to secure treatment compliance, the Supreme Court's decision in *L.C. v. Olmstead*[28] suggests that such an approach may violate the Americans with Disabilities Act (ADA).

On June 22, 1999, the United States Supreme Court held in *Olmstead* that the unnecessary segregation of people with disabilities in institutions may constitute discrimination based on disability. The court ruled that integration is

fundamental to the purposes of the Americans with Disabilities Act, and that states may be required to provide community-based services rather than institutional placements for individuals with disabilities. The decision has far-reaching consequences for how states provide housing for people being discharged from state institutions, and for those at risk of being institutionalized.

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 Americans with Disabilities Act (ADA).

The ADA says, among other things, that

> ...no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be subjected to discrimination by any such entity. 42 U.S.C.A. § 12132

Congress instructed the Department of Justice (DOJ) to promulgate regulations that would provide further guidance on the meaning of this provision of the ADA. Consistent with Section 504 of the Rehabilitation Act of 1973 (which governs recipients of federal funds), DOJ's regulations provide that

> A public entity shall administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities. 28 C.F.R. § 130(d)

DOJ defined "most integrated setting" to mean

> ...a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible. 28 C.F.R. pt. 35, App. A, p. 450

The Supreme Court concluded that "unjustified isolation...is properly regarded as discrimination based on disability." In determining that the ADA required community-based housing and supports for people who were unnecessarily institutionalized, 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. 527 U.S. 581, 600-601 (1999)

While the *Olmstead* case involved a state psychiatric hospital, its principles apply equally to other institutions, like residential schools, intermediate care facilities for people with mental retardation, nursing homes, residential treatment programs and congregate or group homes.

Group homes and other congregate housing models which segregate people with disabilities and isolate them from community life can violate the ADA in the same way that larger institutions do, by perpetuating unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life, and because confinement in a restrictive group home severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural enrichment. As one commentator has put it:

> Such homes...are often simply an extension of the institutions left behind. Group homes, halfway houses, quarterway houses, and board and care homes are hardly 'homes' at all. Like institutions, they segregate people with disabilities and confine them with little, if any, attention to individual choice.[29]

Olmstead virtually commands states to offer services in non-institutional settings. A state mental health system that offered community-based treatment *only* in group homes which, by definition, segregate people on the basis of psychiatric diagnosis, would be committing a form of discrimination prohibited by the ADA. That is because the use of large congregate settings perpetuates unwarranted assumptions that residents are incapable or unworthy of participating in community life, and tends to diminish the everyday life activities of the residents.

Presaging the reasoning of *Olmstead*, Carling identified the key ingredients for achieving community integration as including "a focus on consumers' goals and preferences, an individualized and flexible rehabilitation process, and a strong emphasis on normal housing, work and social networks," and suggests that "[i]ntegration of tenants could be measured by the number and type of their relationships and activities that involve people without disabilities."[30]

Consumers who live in congregate housing find that there is often little due process accorded prior to termination or eviction.[31] Where compliance with

treatment is mandated as a condition of keeping housing, consumers are told "it's my way or the highway," and there is typically no established process by which to challenge an adverse decision, or to get a decision by an impartial decisionmaker[32] —a situation exacerbated by the lack of review by a disinterested decisionmaker and the absence of rights/recourse for residents. There is little "procedural justice" in bundled housing, where a person can lose housing for refusing to follow treatment recommendations.[33]

Because of their primary focus on therapeutic services, mental health providers may believe that conditioning occupancy on acceptance of services is an appropriate incentive structure to ensure treatment compliance.[34] The inherent characteristics of the congregate, service-mandated model— "fixed facilities with fixed staffing patterns"[35] —nurture operational practices that mirror those of mental health institutions and do little to prepare consumers to live independently.[36]

While the exercise of leverage is theoretically possible in any housing program, on-site services and a congregate setting are more strongly correlated with coercion. Conversely, when a person with a psychiatric disability is living in an apartment or other independent setting, state and federal law make it much more difficult to use housing as leverage.[37] At the most concrete level, if people with psychiatric disabilities are considered tenants,[38] then state law is likely to prohibit the termination (or threatened termination) of housing for "treatment noncompliance" as long as they were abiding by the basic obligations of tenancy. Many judges would be unlikely to enforce mental health service requirements under these circumstances.[39] In this fashion, the rule of law inhibits the unwarranted use of coercion, and weeds out frivolous attempts to evict or terminate. Without the ability to resort to coercion, mental health systems would have to make more frequent use of constructive engagement strategies to secure compliance with treatment.

In promulgating the ADA regulations, "the Attorney General expressly acknowledged in the ADA rule the obligation of all public entities to modify regular programs and provide auxiliary aids and services for persons with disabilities in regular programs, *even where such program modifications and services already are appropriately offered to persons with disabilities in a segregated setting.* If an individual with a disability chooses not to participate in the separate program, the public entity is required to provide the necessary program modifications and auxiliary aids and services in the regular setting...."[40] As outlined above, the Supreme Court adopted this view in its *Olmstead* decision.

RE-EXAMINING THE CORE VALUES OF COMMUNITY MENTAL HEALTH

Whether out of commitment to a philosophy of person-centered planning, or out of concern for legal liability, state mental health systems are struggling with how to balance old-fashioned ways of thinking with 21st century mandates. Innovative mental health commissioners have committed their states' systems to integrated housing[41] and to ridding the system of coercion (except in emergency circumstances).[42] Such clear and strong statements of values can change the whole system by creating disincentives for frivolous coercion and making it safer to speak out about rights and abuses within the system.

When faced with the question about whether bundling housing and services is effective, our answer has much to say about our aspirations for people with psychiatric disabilities. Certainly, we could put everyone with a diagnosis in a secure congregate facility in the community and claim to be in favor of community integration. However, federal law and common sense suggest that this would be inappropriate. The degree to which a mental health system is prepared to take risks, and to allow consumers to take risks with regard to housing and service use is a fair measure of its commitment to person-centered planning and community integration.[43]

If the housing is conceptualized as permanent, and as a "home" rather than a residential treatment site, then it is counterintuitive to take (or threaten to take) the housing away because of treatment issues. In many cases, it is the very unavailability or withholding of a basic human need—like housing—that exacerbates the symptoms of mental illnesses. How can a system that pledges fealty to the goal of community integration maintain policies that permit such withholding as a form of behavior control? And how can the ethical codes of psychiatrists, psychologists, social workers and other mental health professionals permit them to enforce such policies?[44]

Mental health professionals are called upon to identify appropriate housing for consumers on a regular basis. But when their own conception of what is possible is constrained by a system that thinks in terms of "beds" and "slots" rather than "homes," and where there are powerful, inertial forces with a stake in the current approach, it is not surprising that congregate housing is over-prescribed. A place to restart the inquiry would be to have every mental health system ask itself the following question: "Do individuals with psychiatric disabilities need residential treatment, or do they need help establishing themselves in a place to live that feels like home?"[45]

More and more mental health systems acknowledge that recovery should be an important goal of the mental health system, and at least one model statute makes it the central focus.[46] State agencies adopt such goals, understanding the critical relationship between self-determination and recovery.[47]

WHAT WORKS?

We know that poor housing correlates with poor community adjustment outcomes,[48] and that residents of supportive housing have experienced stability in housing, greater satisfaction and a dramatic reductions in hospital days.[49] Greater choice in housing is also positively correlated with happiness and life satisfaction ratings and, ultimately, with community success.[50] Some research even suggests that client preference may predict success in different housing options better than any other single criterion.[51] Reliance on congregate models has led to poor quality housing in many states.[52]

The irony is that recent research indicates that housing programs serving 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, and which produces outcomes which are significantly better than the old bundled models.

Pathways to Housing has demonstrated that such outcomes are possible, even for people coming in directly off the street, and even in a hyper-inflated market like New York.[53] The 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."[54]

The Pathways study attempted to answer two questions: "First, can homeless individuals who live on the streets and who have psychiatric disabilities or substance addictions successfully obtain and maintain an independent apartment of their own without prior treatment? And second, do housing programs that require clients to participate in psychiatric treatment and maintain sobriety have a greater housing retention rate than a program that first offers clients access to independent living without requiring treatment?"[55]

The result: "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 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."[56]

Most importantly, "[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."[57] Ironically, Pathways' commitment to providing permanent housing equips its residents with the skills