Major Mental Illness, Housing, and Supports

The Promise of Community Integration

Paul J. Carling

Center for Community Change through Housing and Support, University of Vermont

ABSTRACT: Providing housing and supports for people with psychiatric disabilities, particularly those who are homeless, is a major public policy challenge. This article summarizes the ways in which the concept of these needs is rapidly shifting in the mental health field. The article is based on research on the effectiveness of non-facilitybased community support and rehabilitation approaches, the findings of other disability fields, and the emergence of mental health consumers' own preferences for expanded choices, normal housing, and more responsive services, including consumer-operated services. These new sources of knowledge are facilitating a paradigm shift in which people with psychiatric disabilities are no longer seen as hopeless, or merely as service recipients, but rather as citizens with a capacity for full community participation and integration.

This article summarizes emerging trends in providing citizens with psychiatric disabilities with decent, affordable housing and the support needed to lead satisfying lives. Meeting these needs is a significant public policy challenge. On one hand, investigators in the field debate the failure of deinstitutionalization and the need for asylum (e.g., Wasow, 1986; Zipple, Carling, & McDonald, 1987), the crisis of homelessness (Bachrach, 1984; Baxter & Hopper, 1984), the low quality of community and hospital programs (Torrey & Wolfe, 1988), and the orientation toward maintenance rather than rehabilitation (Anthony & Blanch, 1989). Although mental health policies stress the need for community support systems (National Association of State Mental Health Program Directors, 1986), most resources are still used for institutional programs (Carling, Randolph, Blanch, & Ridgway, 1987) and model community support programs are rare (Bachrach, 1980). The lack of attention to consumers' rights is also debated (Chamberlin, 1978; Leete, 1989). On the other hand, investigators see the development of more effective community support services (Stein & Test, 1985), attention to consumer empowerment (Leete, 1989), respectful clinical interventions (Anthony & Blanch, 1989; Strauss, 1989), and a clearer emphasis on meeting basic needs for homes, jobs, and friends (Taylor, Racino, Knoll, & Lutfiyya, 1987; Wilson, in press).

Considering these dramatically conflicting views, it has been suggested that the field is in the midst of a "paradigm shift" (Blanch, Carling, & Ridgway, 1988; Carling, 1989; Carling, in press) from an era of institutional and

facility-based thinking, to a transitional period in which people were seen principally as service recipients needing a professional support system (Stroul, 1989; Turner & TenHoor, 1979), to a world view in which people are seen as citizens with a potential for, and a right to, full community participation and integration (Carling, 1987; Wilson, in press).

Background and Scope of the Problem

Since the late 1950s, the United States has significantly reduced public hospital use and expanded community services, (Kiesler, 1982), A focus on stable housing linked to supports, however, has only emerged in the last 10 years (Carling & Ridgway, 1987). A majority of the 1.7 to 2.4 million Americans considered long-term mentally ill on the basis of diagnosis, disability, and duration of disorder (Goldman, Gatozzi, & Taube, 1981) live in inadequate housing, lack needed supports, or are homeless (U.S. Department of Health and Human Services [DHHS], 1983; DHHS Steering Committee on the Chronically Mentally Ill, 1980). The problem is a complex one: Without active rehabilitation, many individuals lack the skills and supports needed for successful community living. The recurring nature of psychiatric disabilities, with repeated hospitalizations, may also result in the loss of housing (Budson, 1981; Chatetz & Goldfinger, 1984). Housing discrimination is rampant, as many landlords refuse to rent to mentally ill individuals (Aviram & Segal, 1973; Hogan, 1985a, 1985b; Segal, Baumohl, & Moyles, 1980). Most people with psychiatric disabilities are poor; their average annual incomes range from \$3,000 to \$7,000, and their unemployment rates are as high as 85% (Anthony & Dion, 1986).

Failure to focus on decent and stable housing means that as many as one third of inpatients remain in psychiatric hospitals unnecessarily (DHHS Steering Committee, 1980). Others cycle through emergency rooms and general hospitals in costly and often inappropriate stays (Chatetz & Goldfinger, 1984; Geller, 1982). Still others are placed in custodial nursing and boarding homes that lack rehabilitation or treatment facilities, contribute to declines in functioning, and are often exploitative (Carling, 1981; Kohen & Paul, 1976; Segal & Aviram, 1978; U.S. Senate Special Committee on Aging, 1976). The lack of stable housing and support substantially burdens families (Hatfield, Fierstein, & Johnson, 1982; Wasow, 1982) that serve as case managers and landlords. Those mentally ill individuals who do find housing often live in very low

income neighborhoods with substandard dwellings and high crime rates. Oversaturation of these neighborhoods by people with disabilities often leads to community backlash (Coulton, Holland, & Fitch, 1984; Ridgway, 1987). An increasing number are homeless; studies report that as few as 10% and as many of 75% of people who are homeless have severe psychiatric disabilities (U.S. General Accounting Office, 1988), although they have not necessarily used mental hospitals (Baxter & Hopper, 1984). Finally, these individuals compete for housing with individuals from other low-income groups, most of whom are generally viewed as more suitable tenants.

The Affordable Housing Crisis

These housing problems are compounded by dramatic changes in the current housing scene, in which a decadelong decline in affordable housing stock and the rising cost of housing in relation to income have reduced access to decent housing for all people with limited incomes. Home ownership is now out of reach of the middle class, and decent housing is out of reach for most people at or below the poverty level. These trends have included a cut of nearly 80% in federally assisted housing for low-income and special-needs groups since 1981, and a dramatic increase in homelessness in all parts of the country (Low Income Housing Information Service, 1988). Because disabilities can be economically catastrophic, people with disabilities are disproportionately represented among the very poor (i.e., those with 20% or less of median income) and even lack access to affordable housing programs, which typically require 50% to 80% of median income. Paradoxically, since access to affordable housing has become a national crisis, the public's support for increased federal and state spending and taxation for this purpose has risen to an all-time high (National Housing Institute, 1988). Thus, even as federal housing programs were being cut in 1988, Congress was drafting sweeping new affordable housing legislation to reverse these trends (Carling, 1988). These developments represent an important opportunity to introduce innovative strategies for more successful community integration to the public agenda through a focus on housing.

Mental Health's Response

Historically, the mental health field has seen housing as a social welfare problem and has defined its role as treatment. The public housing field, reflecting societal stigma, contends that mental health consumers need specialized residential programs, for which mental health is respon-

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Correspondence concerning this article should be addressed to Paul J. Carling, Center for Community Change through Housing and Support, Department of Psychology, University of Vermont, John Dewey Hall, Burlington, VT 05405-0134.

sible (Carling & Ridgway, 1987). Thus, housing needs are ignored: Residential services are typically treatment facilities, not housing. Transitional halfway houses proliferated in the 1960s. In the 1970s, the concept of a residential continuum emerged, including quarterway houses and halfway houses (Budson, 1981), three-quarterway houses (Campbell, 1981), family foster care (Carling, 1984; Linn, Klett, & Caffey, 1980), crisis alternative models (Stein & Test, 1985; Test, 1981), Fairweather Lodges (Fairweather, 1980), apartment programs (Carling, 1978; Goldmeier, Shore, & Mannino, 1977), boarding homes (Kohen & Paul, 1976), nursing homes (Carling, 1981), and homeless shelters (Bachrach, 1984). These programs have typically been segregated, professionally staffed, and congregate in nature (Carling & Ridgway, 1987).

The Current State of Practice

A recent national survey of more than 2,500 community residential programs in all states serving adults with psychiatric disabilities (Randolph, Sanford, Simoneau, Ridgway, & Carling, 1988) found that a relatively small number of agencies provide these services in most states. In spite of the continuum model, few agencies offer more than one option. Most programs were large congregate facilities, accounting for less than one fourth of the settings but most of the residents. Newer supervised apartment programs used larger numbers of standard-sized households, an approach that is more consistent with normalization principles (Taylor et al., 1987; Turner & TenHoor, 1979). Intermediate care facilities, nursing homes, and shelters had few formal ties with mental health services. Transitional housing, with time limits, was not as common as expected. Most programs provided services on a long-term basis. Residential services, although assumed to be intensive, were staffed primarily by paraprofessionals who had not been trained in the traditional mental-health core disciplines. Follow-up services were essentially informal, suggesting that efforts to assist clients to find and maintain stable housing may be relatively weak. Sixty thousand individuals received services from these residential programs. Extrapolating that figure to the survey universe reveals that, nationally, fewer than 5% of people with psychiatric disabilities live in such settings (Goldman et al., 1981). This is consistent with state estimates that between 2% and 5% of people with psychiatric disabilities are served in residential programs (Ridgway, 1986). Individuals served were primarily young adults with diagnoses of major mental disorders. Using a functional rating scale, more than one half of the programs served persons with moderate to severe disabilities. The rest served people who were either gravely disabled or functional. Surprisingly, these programs served twice as many persons who were functional as they did those who were gravely disabled. This finding contradicts the popular notion that residential programs are serving those with severe disabilities, and it raises serious concerns as to whether such scarce resources should be serving so many persons who are functioning relatively well.

Evaluation of Current Residential Program Approaches

Our knowledge about what works in residential programs is hampered by both methodological and conceptual problems. Few evaluations of community residential services have been rigorous enough for conclusions to be drawn (Braun et al., 1981; Kiesler, 1982; Test & Stein, 1978). Also, as the goals of community programs are rarely well defined, most outcome evaluations have been conceptually flawed. The most frequent evaluation question is whether community programs are more successful than institutional treatment in helping individuals achieve more independent living. In six major reviews covering several hundred alternatives to hospitalization, only a handful of studies met basic criteria of experimental design (Braun et al., 1981; Carpenter, 1978; Dellario & Anthony, 1981; Kiesler, 1982; Test & Stein, 1978). Taken as a whole, these studies indicate that community-based treatment is virtually always as effective or more effective than hospital-based treatment in helping people with psychiatric disabilities to achieve employment outcomes, to gain re-entry into the community, and to reduce the use of medication and outpatient services. Apparently, any of a wide range of community services can assist in achieving some measure of community integration.

With regard to residential programs, Cometa, Morrison, and Ziskoven (1979), reviewing 109 studies, concluded that evidence of the effectiveness of transitional halfway houses in reducing recidivism, improving economic self-sufficiency, and improving community adjustment was "highly suspect" (p. 25). Transitional residential programs may in fact be preferable to institutional care, but according to Cometa et al. they fall considerably short of helping people to achieve lasting community integration.

Perhaps the most intriguing findings in this area come from an extensive study of sheltered care environments conducted by Segal and Aviram (1978) and a review by Tabor (1980) that indicated that characteristics of the community are more important than characteristics of residents in predicting the degree to which people actually participate in community life and that specific characteristics of the facility were the least important factor. These studies suggest that outcome research should be reframed to focus on where people live and how they spend their time, rather than only on the interventions that professionals provide. There have been few rigorous evaluations of specific residential programs and virtually no attempts to examine professionals' success in helping people to get and keep normal housing. This lack of information on program effectiveness is a critical deficit that can result in grossly inefficient use of resources and, most important, seriously curtailed opportunities for people with psychiatric disabilities.

Problems with Traditional Approaches

Despite the growth of residential services and the emergence of new models, residential programs do not, per

se, meet housing needs. In fact, serious questions have been raised about confusing residential treatment with housing, or assuming that people need such programs prior to independent living (Taylor et al., 1987). The growing acceptance of a rehabilitation approach (Anthony & Jensen, 1984; Blanch et al., 1988) demystifies acquiring stable housing by defining it as a process of building critical skills and supports to choose, get, and keep the housing one desires. A range of research and training activities undertaken by the Center for Community Change (CCC) at the University of Vermont, partly in collaboration with Boston University's Center for Psychiatric Rehabilitation. has revealed significant dissatisfaction among consumers, their families, and service providers with the concept of a residential continuum, and with the transitional services model. In a summary, Carling and Ridgway (1987) criticized the transitional stay in residential settings as a simplistic approach to independent living that creates major difficulties for the individual, including (a) having to learn skills that are mostly relevant to group living; (b) chronic dislocation through successive moves, because improvement in functioning requires a physical move; and (c) an ultimate return to family, boarding home, hospital, or homelessness, because of the inattention of many treatment-oriented systems to stable housing. Similarly, the residential continuum allocates resources to separate facilities rather than to services and supports linked to normal housing. The transition and the continuum concepts often require participation in a service program in order to receive housing. These findings are echoed in the literature on developmental disabilities (Taylor et al., 1987). On the basis of these findings, Randolph, Zipple, et al. (1988) recommended that the field move away from the concepts of a residential continuum and transitional and congregate programming, focus instead on housing and supports, and make consumers' preferences the single most important determinant of the housing and support options available.

Recent Mental Health and Cross-Disability Literature

Two recent reviews of the research on psychiatric disabilities (Anthony & Blanch, 1989; Wilson, in press) summarized effective ways to provide people with decent housing and ongoing support, and concluded that (a) this disability is not a life-long degenerative process: (b) most mentally ill people can maintain homes, jobs, and friendships: (c) services must be highly flexible to respond to individual needs (people with the most severe disabilities need the most individualized approaches); (d) people can make positive choices about needed supports; and (e) people don't define themselves principally as chronic mental patients, and value independence and productivity more than any other treatment outcomes.

Mental health also has much to learn from other groups who need special supports in their housing, including people with low incomes, elderly people, homeless people, and those with developmental disabilities, including mental retardation. A recent review of the re-

search on housing and community integration for all disability groups (Carling et al., 1987) concluded that

- Housing needs are similar for all groups, although support needs vary.
- 2. Supports are the critical determinant of whether people can remain in their chosen housing.
- 3. Housing problems relate less closely to disability than to economic and social factors such as poverty, affordable housing, and discrimination.
- 4. Strong differences of opinion often exist between professionals and consumers about specific needs for housing and supports, regardless of disability group.
- 5. Choices and control over one's environment are necessities; consumers want to be centrally involved in planning and managing their own housing and services.
- 6. Senior citizens and people with disabilities, without in-home supports, are plagued by transience, dislocation, and the risk of institutionalization.
- 7. The model of a residential continuum is increasingly beset by conceptual and practical problems.

This review concluded that the broader disability community increasingly emphasizes normal housing and the need to avoid transforming housing into service settings. Community integration approaches should avoid congregation and segregation and focus on building relationships between disabled and nondisabled individuals.

Consumer Preferences

Consumers own preferences are emerging as a powerful determinant of the need for housing and supports. In a countywide needs assessment in the state of Washington, Daniels and Carling (1986) reported on data from providers and their clients about their perceptions of the need for housing and supports. Professionals and consumers held virtually opposite views about housing and support needs, with professionals favoring transitional, highly staffed residential programs for the great majority of consumers, and consumers expressing preference for normal housing with flexible supports. Most consumers preferred to live with one other person rather than live alone or in a larger group. Recently, the first statewide study of consumers' preferences for housing and supports was conducted in Vermont (Tanzman, Wilson, & Yoe, in press), involving a random sample of individuals who were homeless, in the state hospital, or receiving community services. Most persons preferred to live in their own apartment or house (and, given financial support, to own their own housing) rather than in a mental-health-operated facility, single-room-occupancy hotel (SRO), or community-care (boarding) home, or with their family. The major barrier consumers saw to realizing this preference was a lack of adequate income. Most people wanted to move to a better location, have more space in better repair, and have more freedom and autonomy. People in SROs were least satisfied of all respondents, including those who were in the state hospital or homeless. The most preferred characteristics of living situations were freedom and autonomy, permanence, security, and privacy.

Traditionally, the field has assumed that many people need live-in staff to assist them during crises and to teach them skills. Only one tenth of the respondents, however, wanted live-in staff. Most preferred that staff be available by telephone, or in person if necessary, on a 24-hr basis. As contrasted with traditional placement into group settings, most people preferred not to live with other consumers, feeling that it was difficult enough to cope with their own problems. Instead, they wanted to live with a friend or romantic partner. From this study and more than 30 similar and as yet unpublished studies reviewed by Center staff, it is clear that consumers, whether homeless, in a state hospital, or in community programs, can articulate their needs for housing and supports.

Finally, consumer perspectives were solicited in a national housing policy forum (Ridgway, 1988) attended by a group of nationally recognized consumer leaders. Individuals recounted their own experiences with homelessness and residential programs and concluded with the following recommendations. The group felt that providers should develop the housing options that most people prefer (independent or shared apartments with support services); that housing should be decent and permanent; and that it should be developed in neighborhoods that were safe and near shopping, services, and transportation. They urged that support services focus on helping people develop skills, manage stress, deal with landlords, manage money, and seek support. With regard to income, the group urged that disability benefit levels be improved and that special funds be made available to help people move into and keep housing (including loan funds for security deposits, rent subsidies, and employment opportunities). Participants called for improved case management with lower caseloads and higher pay and urged the creation of new staff roles, such as a personal-care attendant model. They urged that staff be specifically trained to help people choose, acquire, and keep housing, and to value and respond to the consumers' perspectives on needs. They also recommended that consumers be hired and trained as service providers, outreach workers, case managers, skills teachers, and program managers. They called for the development of self-help options, including user-run housing. They pressed for increasing consumers' input into decision making, by conducting housing forums, using expatients to collect information, and by always involving consumers in planning and developing housing and supports. They encouraged public education efforts to reduce stigma, including educating public officials about consumers' concerns. The group sought tighter regulation of board and care homes and emphasized the need for further legislation for affordable housing. Finally, they stressed the importance of working in coalitions and keeping the public's awareness of this issue at a high level.

Emergence of a Supported Housing Approach

In summary, findings from community support and rehabilitation literature in mental health, from other fields, and from consumers themselves suggest that the key ingredients of community integration are a focus on consumer goals and preferences, an individualized and flexible rehabilitation process, and a strong emphasis on normal housing, work, and social networks (Blanch et al., 1988; Carling et al., 1987). In the field of mental health, this approach has been termed supported housing (National Institute of Mental Health, 1987). The National Association of State Mental Health Program Directors (1987) recently approved a policy statement that sharpens their focus and endorses the concept of supported housing. It reads

All people with long-term mental illness should be given the option to live in decent, stable, affordable and safe housing, in settings that maximize their integration into community activities and their ability to function independently. Housing options should not require time limits for moving to another housing option. People should not be required to change living situations or lose housing options when their service needs change, and should not lose their place of residence if they are hospitalized. People should be given the opportunity to actively participate in the selection of their housing arrangements from among those living environments available to the general public. . . . Necessary supports, including case management, onsite crisis intervention, and rehabilitation services should be available at appropriate levels and for as long as needed by persons with psychiatric disabilities, regardless of their choices of living arrangements. Services should be flexible, individualized and provided with attention to personal dignity. Advocacy, community education and resource development should be continuous. (pp. 1-2)

Thus, supported housing is organized around three central principles: (a) consumers choosing their own living situations; (b) consumers living in normal, stable housing, not in mental health programs; and (c) consumers having the services and supports required to maximize their opportunities for success over time. Two recent reviews of characteristics of local supported housing programs (Blanch et al., 1988) and related state-level innovations (Carling & Wilson, 1988) provide information on the specifics of this approach.

Implications for Public Policy

Traditional funding streams, program requirements, administrative approaches to resource allocation and management, and even staff skills are not oriented toward intensive support for consumers in normal housing and work settings (Carling & Wilson, 1988). Systems that are moving toward a supported housing approach face significant challenges. Such systems, rather than developing more residential programs, often emphasize developing better community services, increasing consumers' income through employment and subsidies, building relationships with the public and private housing sectors to access and

develop housing, focusing on tangible outcomes from their service providers, and restructuring their policies, funding, and regulations to be consistent with these outcomes. Systems that have moved even further have curtailed future group home development or have begun decongregating these programs (Nagy & Gates, in press; Ohio Mental Health Housing Task Force, 1986). Key to success is a clear mission that articulates the role of consumers in this process, and the housing options and types of services that will actually be available.

Need for Further Research

As public policy shifts away from an expectation that residential facilities will meet the need for stable housing and community supports, more research is needed in the areas of consumers' preferences; successful strategies for facilitating meaningful client choices, developing housing and supports, and developing relationships with people without disabilities; documentation of the costs and benefits of housing and support initiatives; identification of clinical interventions best suited to normal housing; and an elaboration of the role of peer support in community success. Research on supported housing, to date, has largely consisted of descriptive studies of current programs (Carling, 1990; Hall, Nelson, & Fowler, 1987). This is appropriate given the early state of evolution of the supported housing approach. In order to demonstrate the effectiveness of this approach, further studies that assist the field in operationally defining this set of concepts, as well as studies that assess its impact on consumers and their families, are essential. Carling et al., (1987) concluded that further research is not needed on hospital versus community alternatives or on the efficacy of residential treatment settings (e.g., group homes), particularly as these settings are so rarely operationally defined. The key unresearched questions, according to that review, are "Where do people with mental illness live?"; "Where do they want to live?"; and "How can we help them succeed there?" (p. 23). In the final analysis, this will require a shift from professionally defined to consumer-defined research, focusing more on the commonalities between people with and without disabilities, and defining success in terms of those aspects of quality of life that are important to all citizens.

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