An Overview of Surveys of Mental Health Consumers' Preferences for Housing and Support Services

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Objective: *The author examined the methodology and results of studies that surveyed mentally ill clients' preferences related to housing and support services to gain an overview of demographic characteristics, current and preferred housing situations, and preferred types of staff supports and social and material supports in a nationally representative sample of clients.* *Methods:* *Through mailings to state departments of mental health and local mental health providers and advocates, a national survey of residential providers, and other contacts with mental health agencies, the author identified a total of 43 studies of mental health consumers' preferences for housing and supports conducted between 1986 and 1992. The results of 26 of the studies whose methodologies permitted comparison of findings were summarized.* *Results:* *Consumers consistently reported that they would prefer to live in their own house or apartment, to live alone or with a spouse or romantic partner, and not to live with other mental health consumers. Consumers reported a strong preference for outreach staff support that is available on call; few respondents wanted to live with staff. Consumers also emphasized the importance of material supports such as money, rent subsidies, telephones, and transportation for successful community living.* *Conclusions:* *To accommodate consumers' preferences, mental health systems should work toward providing flexible supports corresponding to the episodic nature of psychiatric disability and should expand their advocacy for affordable housing and for increased income for people who depend on disability benefits and other entitlements.*

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Mental health services are increasingly implementing policies that reflect "consumer-driven" or "client-centered" systems. The growth of research on consumers' preferences in the areas of housing and support services echoes this shift and mirrors the increased attention to housing issues in the mental health field in the 1980s and 1990s.

During these years the downsizing of state psychiatric hospitals and the concomitant growth in community-based comprehensive mental health systems increased the demand for housing alternatives. The number of residential services offered by mental health agencies increased, yet these agencies provided residential services to fewer than 5 percent of Americans with psychiatric disabilities in 1986–87 (1).

The shortage of residential services persists in the context of a worsening crisis in the availability of affordable housing (2). This crisis places people with psychiatric disabilities, many of whom have little income, at high risk for homelessness (3,4). Lack of stable affordable housing for people with psychiatric disabilities undermines the effectiveness of rehabilitation and other mental health services and contributes to the problem of inappropriate institutionalization (5,6).

The need for more housing options for people with psychiatric disabilities is hardly under debate, but the most useful way to provide these options is considerably less certain. Although services should be designed to meet the needs of those they serve, mental health services research has historically relied on service providers as key informants and has been slow to incorporate client and family perspectives (7). A few studies of consumers' preferences in the areas of housing and supports were conducted in the mid-1980s (8–12). In the past few years the number of such studies has grown; our research shows that by 1992 at least 43 studies on consumers' housing and support preferences were completed in 24 states and two Canadian provinces (13–51).

States, counties, and cities that sponsor such research have the benefit of consumer views while making strategic decisions about how to invest resources in times of fiscal constraint. Research on consumers' preferences is also important because consumers and professionals often have different views of consumers' needs and of the most helpful types of interventions to address those needs (52–55). The validity of consumers' assessments of their own situations and needs has been underscored in studies of community-based treatment programs (56,57).

Information from consumers can help in planning more effective services and in increasing consumers' cooperation with service plans (58, 59). In planning rehabilitation services, mental health systems have in-

creasingly valued perspectives that emphasize individual consumer choice and motivation, recognize the tenuous relationship between diagnosis and prognosis, and focus interventions on building personal strengths as well as reducing psychiatric symptomatology (60–65). The increase in research on consumers' housing and support preferences also reflects the rise of advocacy movements of consumers and family members, who are demanding a greater role in decisions that affect their lives.

This paper gives an overview of the characteristics and findings of 43 survey studies of consumers' housing and supports preferences conducted between 1986 and 1992. Most of the studies represent the first time the sponsoring mental health system directly asked consumers about their preferences for housing and supports.

Methods

The basic instrument. The Center for Community Change Through Housing and Support is a national organization whose mission is research, knowledge dissemination, and technical assistance focused on housing, supports, and community integration for people with psychiatric disabilities. Center activities began jointly with the Boston University Center for Psychiatric Rehabilitation in 1984 and were consolidated at the University of Vermont in 1987. In 1992 the center relocated to Trinity College of Vermont. The center is funded through contracts with state and local mental health systems and federal research and knowledge dissemination grants.

In 1988, with the support of a field-initiated research grant from the National Institute of Disability Rehabilitation and Research and the Vermont Division of Mental Health, the center developed methods and a survey instrument to assess consumers' housing and support preferences and implemented a consumer preference study in Vermont (51). Consumers were employed as interviewers and research assistants. The interrater reliability of consumer interviewers recording respondents' verbal replies in the Vermont study was an excellent 96.8 percent (66). The instrument and methodology were described in a practical guide (67) and disseminated nationally through the Technical Assistance Center on Housing and Supports funded by the National Institute on Mental Health.

The center's basic instrument is a 42-item questionnaire that uses multiple-choice, 3- and 5-point scales, and open-ended response formats. It requests information on respondents' demographic characteristics, current housing situation, current use of support services, preferred housing arrangement, and preferred support services.

Sample of the studies. The author maintained contact with the states and localities that implemented consumer preference studies using the center's instrument and methodology. In addition, information and findings from consumer preference surveys were systematically solicited through a national survey of 676 residential providers (68), a mailing to 4,000 state and local mental health agencies in 1988, and regular mailings to designated housing coordinators in each state department of mental health. The author identified 43 consumer housing and support preference studies through these contacts.

Results

Characteristics of the studies

Instruments used. Twenty of the 43 studies used the instrument developed by the Center for Community Change with minor modifications. Eight used an earlier version of the instrument developed by the center's forerunner, the Community Residential Rehabilitation Project at Boston University's Center for Psychiatric Rehabilitation. The remaining studies either developed their own instruments or used a highly modified version of the center's instrument.

Procedures. Thirty-five of the studies used interviews, and eight used self-administered mail questionnaires or questionnaires completed at a group meeting. Of the studies based on interviews, 18 used consumers and former patients as interviewers, 15 used staff or research assistants, and two used both consumer and staff interviewers. Most of the studies were commissioned by state or county offices of mental health, although five were sponsored by individual public agencies. In most settings, funding for research was limited, and large in-kind contributions of staff time, data processing, printing, and telephone resources were required from agencies and consumers to complete the research.

Samples. Twenty studies used no sampling strategy but collected data from convenience samples composed of willing individuals who used mental health services. Five studies collected information from the total target population, often the total population being treated in an inpatient unit or specific program. Seventeen studies used random sampling techniques. One study used a purposive quota sample that proportionately reflected the actual distribution of consumers' current housing situations.

The most common procedure for contacting respondents, used by 29 studies, was for the research staff to invite consumers to participate in the survey during the normal course of service provision. Ten studies used mail and phone contact to solicit respondents' participation; four primarily used group meetings and word of mouth.

Scope. The geographic scope of the studies varied. Half of the studies covered a county or city, 16 drew statewide samples, and five were limited to consumers served by individual agencies. Twenty studies surveyed fewer than 100 respondents, 18 studies had samples of between 100 and 300 respondents, and five studies surveyed more than 300 consumers.

Almost all of the studies, 40 of 43, drew their samples from among people who were receiving mental health services from a variety of outpatient programs, including residential and day programs and medication management programs. Two studies targeted members of self-help groups, some of whom did not receive formal mental health services. Eleven studies targeted inpa-

tients at state or regional psychiatric hospitals, and five targeted people who were homeless and had psychiatric disabilities.

None of the studies reported problems with unusable data, uncooperative respondents, or answers that seemed delusional. In most cases, the informed consent and respondent notification procedures succeeded in engaging willing and able participants.

Findings of the studies

Seventeen of the 43 studies were excluded from detailed analysis for various reasons. The findings from three of those studies (28,33,50) were not available when this paper was prepared. A study focusing on homeless women in Toronto shelters was excluded because the sample included women without psychiatric disabilities (27). The findings of one study were used for individual discharge plans from an inpatient setting (23), and another study (24) used the findings for housing plans for individuals leaving homeless shelters. Neither of these studies reported group preferences.

Eleven studies were not comparable with the majority of the studies because they used unique survey instruments or adapted survey questions in unique ways (8–13,15,17, 19,22,34). For example, some surveys reported only the housing preferences of respondents who said they wanted to move. Other surveys elicited housing preferences but not information about preferences for supports or services. However, in these 11 studies, the most frequent response to the question of housing preference was "my own house or apartment." In ten of these studies, the preference for independent housing was cited more than twice as often as any other housing arrangement.

The research methods and instruments used by the 26 remaining studies were similar enough that their findings could be compared. The findings summarized below are organized into six categories: demographic characteristics, current housing, preferred housing, housemates, staff supports, and social and material supports.

Demographic characteristics. The 26 studies represent considerable geographic diversity. They were conducted in 17 states in the Midwest, Northeast, West, and South, and in one Canadian province. Rural areas were represented by studies in Alaska (43), Mississippi (20), and Vermont (35, 66). The urban areas included Cleveland (45), Milwaukee (36), Raleigh-Durham, North Carolina (21), Tampa Bay, Florida (29), Boston (38), and the San Francisco Bay Area (16).

These 26 studies surveyed a total of 4,438 adults with psychiatric disabilities who used inpatient and outpatient public mental health services. Fifty-one percent of the survey respondents were men, similar to the proportion of men among clients in community support programs nationally in 1984 (69).

Data on race were available for 3,215 survey respondents. Sixty-three percent were Caucasian, 29 percent were African American, 3 percent were Native American, 2 percent were Hispanic, less than 1 percent were Asian, and 3 percent had other racial backgrounds. For comparison, 82 percent of clients in community support programs in 1984 were Caucasian, 11 percent were African American, 6 percent were Hispanic, and 1 percent had other racial backgrounds (69). Thus African Americans may be overrepresented and Caucasians underrepresented in the studies reviewed here.

Respondents' ages ranged from 18 to 84 years, with most under 50 years old. The mean ages ranged from 34 to 42 years; thus the samples were on average younger than the community support program clients surveyed in 1984, whose mean age was 41.2 years (69). At least 60 percent of the respondents in each of the studies we reviewed reported that disability benefits and other entitlements such as Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI) were their main sources of income. Mean incomes for the samples ranged from $271 to $679 per month. In comparison, 66 percent of the community support programs clients surveyed in 1984 derived their incomes from SSI and SSDI; their mean monthly income was $429 (69).

The large size of the sample in the combined studies, in addition to the geographic and demographic diversity represented, suggests that the findings we report can reasonably be applied to the national population of adults with psychiatric disabilities currently receiving public mental health services.

Current housing arrangement. The most frequently reported current housing arrangement was independent living or living in the respondent's own house or apartment. Between 17 and 82 percent of the respondents in the 26 study samples lived in their own house or apartment, with the proportion in most studies ranging between 35 and 50 percent.

The exceptions to this trend were six studies that targeted people who were hospitalized or homeless or who lived in board-and-care homes or other group facilities (12,15,35,47, 49,51). These studies most likely overrepresent people in institutional or residential settings sponsored by mental health agencies because they are more easily accessed in surveys.

The second most frequently reported current housing arrangement was living with family. The proportion of the study populations in this housing arrangement ranged between 15 and 35 percent. Board-and-care facilities, the third most frequently reported arrangement, were mentioned by between 0 and 35 percent of the respondents in each study.

Preferred housing arrangement. Despite the variety of target populations, sampling strategies, implementation methods, and geographic regions, strikingly little variation in respondents' housing preferences existed among studies. The most preferred housing arrangement in every study was independent living in a house or apartment. In 24 of the 26 studies, at least 59 percent of the sample preferred to live in their own house or apartment. In 20 of the studies, at least 70 percent of the sample mentioned this preference.

In 11 studies, the second most preferred arrangement was living

with family; between 4 and 19 percent of the samples reported this preference. In four studies, board-and-care homes were the second most preferred living arrangement, with 5 to 10 percent of the sample reporting this preference. In another four studies, the second most preferred living arrangement was a group home, named by 7 to 28 percent. However, in 21 of the 26 studies, group homes were among the least popular options, named by 0 to 7 percent. In addition, single-room-occupancy housing was not very popular: in 22 studies, only between 0 and 7 percent preferred this option. The least preferred housing options across all studies were hospitals and being homeless.

Housemates. In 16 of the 22 studies in which this issue was addressed, the majority of respondents, 20 to 56 percent, preferred to live alone. In another four studies, the most preferred housemate was a spouse or romantic partner, mentioned by 21 to 46 percent of respondents. In two studies, the most popular housemates were family members.

Sixteen of the studies asked respondents if they would prefer to live with other consumers. In 14 studies, most consumers reported that they would prefer not to live with other consumers. In two studies, more consumers preferred to live with other mental health consumers than with nonconsumers.

Staff support. Respondents were asked to identify what supports they would need to succeed in their preferred housing arrangement. In 22 studies, the two most frequently cited staff-related supports were the ability to reach staff any time of the day or night and help in dealing with emotional upsets and crises. Between 64 and 96 percent of respondents in each study reported needing these two supports.

The next most frequently cited supports in all 26 studies were the availability of staff to come to the respondent's home any time of the day or night and help in budgeting money. Forty-two to 78 percent of respondents said that they would need these supports to succeed in their preferred housing arrangement.

Thirty to 55 percent of respondents from each study reported needing regular home visits from staff, and 16 to 47 percent reported needing help managing medications. Relatively fewer respondents reported that they would need help with cooking (21 to 45 percent) and shopping (18 to 53 percent). The least cited support in each study was live-in staff, named by between 0 and 26 percent of respondents.

Material supports. In every study the most frequently cited material supports were more income and benefits and money for a deposit on housing. Fifty to 95 percent of respondents in the 26 studies said they would need more financial resources to succeed in their preferred housing arrangement. In 21 studies, more than three-quarters of the respondents cited this need.

The second most frequently identified supports were telephones and transportation, cited by more than 50 percent of the respondents in each study. Between 30 and 90 percent said that they would need help finding a place to live. In addition, between 27 and 57 percent said they would need help making friends and getting along with people to succeed in the housing arrangement of their choice.

Discussion and conclusions

Findings from recent studies on consumers' housing and support preferences show that a majority of consumers of mental health services prefer to live in their own apartments or houses and not in residential mental health programs or facilities. Most respondents would prefer to live alone or with a spouse or romantic partner or friends, reflecting a desire for social integration and participation in typical social roles such as spouse and parent.

Consumers preferred not to live with other mental health consumers, indicating a desire not to be grouped in living situations on the basis of disability. This finding may also reflect a reaction against the practices of traditional residential services, which tend to offer consumers too little choice in decisions about where and with whom they will live. Collectively, these findings suggest that adults with psychiatric disabilities are no different from other Americans in their need and desire for decent, safe, affordable housing.

In addition to housing, consumers may need specific supports and services. Three themes emerge from the findings on supports. First, although consumers strongly prefer independent living arrangements, such arrangements are not construed by respondents as living without support from mental health staff, friends, and family members. Instead, consumers appear to understand that independence is facilitated by supports. The challenge to mental health systems is to support clients effectively wherever they live, rather than limiting support to those people living in traditional residential programs.

The second theme is a consistently strong preference for supports that are available on an as-needed basis, rather than supports that are constantly available. Respondents wanted to be able to reach staff any time during the day or night and, if needed, to have staff visit any time of the day or night. Few respondents wanted to live with staff. The preference for being able to reach staff by phone indicates that consumers want to determine when they need support. This finding underscores the importance of autonomy and control to respondents. Thus the challenge is to provide supports in a flexible manner corresponding to the episodic nature of psychiatric disability.

The third theme emerging from the findings on support preferences is the importance of material supports, such as more income, housing subsidies, transportation, and telephones. Consumers' success in the housing arrangement of their choice may be as much an economic issue as a clinical issue.

Most respondents derived their income from disability benefits. However, there is no county or standard metropolitan statistical area in the United States in which a person who lives on Supplemental Security Income can afford an efficiency apartment if one assumes that 30

percent of a person's income is allocated for rent (2). With mean incomes ranging from $271 to $679 per month, respondents faced a daunting financial struggle to survive in the community.

Mental health systems must consider developing the capacity to offer as much material assistance and housing subsidy to clients who live independently as are provided for clients who live in board-and-care homes, group homes, and other treatment facilities. In addition, mental health providers need to be involved in the development of affordable housing for people with very low incomes (30 percent or less of a region's median income) and in promoting increased income for people who derive all of their income from benefits.

Studies of consumer housing and support preferences show that psychiatric disability does not preclude people from having and expressing preferences. In addition, these studies show that consumers who are asked respectfully and appropriately to participate in research make fine research respondents. Like most people, consumers seem to enjoy the opportunity to think about and share their views on important life issues such as housing.

Although consumers who were employed as interviewers needed additional guidance in conducting interviews, having interviewers who were respondents' peers had several benefits. The arrangement diminished the potential for role bias in the results by ensuring that interviewers had no power or authority over respondents' treatment or use of services. It also increased consumer involvement in mental health services and in issues that affect their lives, provided consumers with opportunities for employment and skill development, and underscored the abilities rather than the disabilities of people with major mental illness.

Research on consumers' housing and support preferences is enhancing the mental health field's knowledge about how consumers adapt in community settings. The findings call attention to the importance of meeting material needs and designing flexible supports that can vary in intensity according to an individual's needs. These studies show that consumers can participate fully in research roles and that consumer perspectives can be effectively incorporated into research and services in mental health. These and similar studies can inform the development of services and may point to more cost-effective and humane allocations of resources in mental health service systems.

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