

# The New Asylums in the Community

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• One-hundred and one residents of a board-and-care home housing psychiatric patients were studied. Of these, 92% were diagnosed as psychotic; 42% have lived there five years or more; and 32% have overt major psychopathologic characteristics. Nine of ten have never lived alone or failed in their last attempt.

A relationship was found between use of a community social rehabilitation program and its distance and provision of transportation. Sixty-one percent have had contact with community vocational rehabilitation but only 12% are still involved. Half of them have no goals for changing anything in their lives; 95% use community facilities, mostly eating places and supermarkets.

Board-and-care homes offer an asylum from life's pressures, a degree of structure, and some treatment, especially medication supervision. For many long-term patients they have taken over the functions of the state hospital.

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The controls and structure of the state hospital may have been necessary for many of the long-term mentally ill before the advent of modern psychoactive drugs. Unfortunately, the ways in which this structure was achieved and the everyday abuses of state hospital life have left scars on the mental health professions as much as on the patients. In any case, when the new drugs appeared<sup>1,2</sup> along with a new philosophy of social treatment,<sup>3</sup> the great majority of the chronic psychotic population was left in an environment that was no longer necessary or appropriate for them. But that didn't mean, as many first thought, that most were now ready to become well-functioning members of the community. There may now be less overt psychosis and less need for external controls, but the questions still remain: to what extent can

the chronically ill cope with pressure, tolerate prolonged interaction with others, and have energy for more than dealing with their psychoses and the simple demands of the world? In particular, what has been the experience of those in board-and-care homes, those products of free enterprise that have sprung up to fill the vacuum created by the emptying out of state hospitals? A recent study in a medium-sized California county showed that approximately one third of the long-term psychiatric patients in the community younger than 65 years of age who were diagnosed as psychotic live in board-and-care homes.<sup>4</sup> To what extent are the lives of these patients limited both by their illnesses and by their environment? To what extent have they been offered treatment and rehabilitation and what have been the results? How do they experience their lives? And what are their concerns?

To begin to answer these questions, the present study focused on 101 persons living in a board-and-care home about 2 miles from the downtown area of Los Angeles. The primary method of study was in-depth psychiatric interviews with each person, all done by the author.

## THE SETTING

Board-and-care home is a term used in California to describe a variety of facilities, many of which house large numbers of psychiatric patients. The number of residents ranges from one to several hundred, though according to the State licensing agency, the majority of patients in Los Angeles are housed in facilities of 50 beds or larger. Board-and-care homes are unlocked and provide a shared room, three meals a day, supervision of medications, and minimal staff supervision.

A board-and-care home was sought that would meet the following criteria: large enough to provide an adequate sample, licensed for younger than age 65 (in California, board-and-care homes are licensed for either age 65 and older, or younger than age 65); an administration that would both permit and cooperate with the study, no other

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research conducted in the board-and-care home, either currently or within the past three years, and location within the central part of Los Angeles so that community facilities would be at least theoretically accessible by bus.

The board-and-care home chosen met all these criteria. Though its capacity was 110 persons, its census during the four months of the study (October 1977 to January 1978) fluctuated between 95 and 102.

No two board-and-care homes are exactly alike. While the facility chosen differs in physical appearance, size, staffing, and some policies from other board-and-care homes in Los Angeles, it is not grossly dissimilar to other board-and-care homes in the area.

The building is a four-story converted apartment house. The ground floor consists primarily of a garage area with a central lobby. About half of the first floor is used for the kitchen and dining areas, offices, and dayrooms; the other half, as well as the entire second and third floors, is used for residents' living quarters. Most apartments have one bedroom and when used to "capacity," house four residents, two in the partitioned-off living room and two in the bedroom. There is staff on duty at all times.

All medication is dispensed by the staff at four fixed times during the day. The meal hours are fixed. Personal funds of most but not all residents are held for them by the staff and dispensed once a week at a fixed time. Otherwise, residents are free to "do their thing," a situation that has been observed in large facilities of this kind elsewhere.<sup>5</sup> There are some organized activities but they are voluntary. There are no bedchecks or curfew. There is a rule that no drinking is allowed on the premises, but this is enforced only when drinking becomes a major problem for the other residents and/or the staff.

### METHOD

After a full explanation of the nature of the study, informed consent was sought from all residents currently living in the facility and then all newly admitted persons until the desired sample was obtained. One-hundred and eight residents were approached; six declined to participate, one had an organic brain syndrome that made meaningful communication impossible, leaving a sample of 101 persons.

An in-depth interview was conducted with each resident. An interview guide was prepared covering demographic data, pertinent history, and all aspects of their current lives. Though all items were covered in the interview guide, an attempt was made to develop an informal, comfortable, and wide-ranging conversation. A second interview was conducted about a month later with all but seven persons who had moved in the interim. There was also much informal chatting with residents in the halls and dayrooms. In addition, the medical records kept in the facility were consulted. These included discharge summaries from referring professionals and institutions, and progress notes by the private psychiatrists who visit the board-and-care home for medication management. Other information was obtained from the staff.

### RESULTS

A summary of the demographic and other pertinent data is given in Table 1. This was neither a young nor an old population; median age was 39 years, with a range of 22 to 63 years. There were almost twice as many men as women. Ninety-two percent had been diagnosed as psychotic, history of hospitalization ranged from 0 to 28 years, with a

Table 1.—Characteristics of the 101 Board-and-Care Home Residents

|  |
|--|
| Age, yr                                  |
| Median, 39                               |
| Range, 22-63                             |
| Sex                                      |
| M (N = 65)                               |
| Median age, 36                           |
| Range, 22-63                             |
| F (N = 36)                               |
| Median age, 46                           |
| Range, 23-63                             |
| Race                                     |
| White (N = 60)                           |
| Black (N = 29)                           |
| Hispanic (N = 11)                        |
| Pacific Asian (N = 1)                    |
| Marital Status                           |
| Married (N = 4)                          |
| Never married (N = 64)                   |
| Divorced or separated (N = 33)           |
| Education                                |
| Median, 4 yr high school                 |
| Range, 3rd grade to 2 yr graduate school |
| Primary diagnosis                        |
| Psychotic (N = 92)                       |
| Alcoholic (N = 4)                        |
| Neurotic (N = 2)                         |
| Personality disorder (N = 3)             |
| Hospitalization (total lifetime)         |
| Median, 18 mo                            |
| Range, 0 (6 persons) to 28 yr            |
| Source of support                        |
| Supplemental Security Income (N = 86)    |
| Social Security Disability (N = 2)       |
| General (county) relief (N = 10)         |
| Veterans Administration (N = 3)          |

median of 18 months; and 86% receive their financial support from Supplemental Security Income. The median length of stay at this board-and-care home is 32 months, with a range of four days to 14 years, ten months; 42% have been here continuously five years or more.

Fifty-five percent have had recent contact with family. That is, they had seen a relative within the past three months. All the relatives of 22% of the sample live out of state; this is not an atypical finding for California.

Sixty-three percent of the residents currently have no contact with a mental health professional other than the psychiatrist who visits the facility for medication management (entirely reimbursed by Medicaid). An additional 16% see both the board-and-care home psychiatrist and a psychologist who also comes to the facility; some see him weekly, most see him monthly, and he also is reimbursed by Medicaid. Fifteen percent see psychiatrists away from the facility, four privately, and the remainder at various clinics. Six percent refuse to see any professional or to take medications. Ninety-two percent have major tranquilizers and/or lithium carbonate prescribed and two percent have only antidepressants or minor tranquilizers prescribed.

Thirty-one percent of the study population had been hospitalized during the past year. As given in Table 2, there is a relationship between this and age; 74% of those younger than 30 years had been hospitalized during the past year as compared with 21% of those 30 and older.

The five-point psychiatric assessment scales developed by Krawiecka et al<sup>6</sup> were used. The presence of severe overt psychopathology was defined as the manifestation of major or severe symptoms in at least two of the following

| Age, yr                    | Hospitalized (%) | Not Hospitalized (%) | Total      |
|----------------------------|------------------|----------------------|------------|
| Younger than 30            | 14 (74)          | 5 (26)               | 19         |
| 30 and older               | 17 (21)          | 65 (79)              | 82         |
| <b>Total (P &lt; .001)</b> | <b>31</b>        | <b>70</b>            | <b>101</b> |

three scales: delusions, hallucinations, and thought disorder (incoherence and irrelevance of speech). With the use of this definition, 32% of the sample exhibited severe overt major psychopathology. (But in only 13% did this cause them to be out of touch with reality in most areas of their lives.)

Twenty-seven percent had never lived alone and 62% had failed in their last attempt at living alone. Thus, almost nine of ten (89%) have either never tried living alone or they had a failure experience the last time they tried.

Five residents never leave the building, but all the others take advantage to varying degrees of being in a community setting. For only 15% does this take the form of using the social, cultural, and recreational facilities of the community; rather it mostly involves going to local supermarkets and eating places for coffee and snacks and personal necessities and taking walks in the neighborhood.

With regard to social rehabilitation, a "natural experiment" had occurred before the study that provided the opportunity to examine the relationship between distance of a community program and attendance. For several years a social rehabilitation program had been run once weekly by a well-established private, nonprofit, psychosocial rehabilitation agency. The program was housed in a church about one block from the board-and-care home and operated only during daylight hours. Its range of activities included a coffee hour, bingo, arts and crafts, table games, and literature and poetry discussion groups. Eight months before the study began, the program was moved some distance away requiring transportation by the board-and-care home van or by bus. One month before the study began, the board-and-care home sold the van for "economy" reasons. Sixty-five patients had been in the home long enough to have participated in this experiment. Fifteen persons (23%) had never attended the program even when it was a block away. Seventeen persons (26%) had attended, usually briefly, and stopped because of dissatisfaction with it and/or because of social anxiety. The remaining 33 persons (51%) went and stayed with the program. Of these, 14 persons (22%) stopped when the program moved. Seventeen persons (26%) who traveled there by the van continued to attend until the van was sold. That left two persons (3%) who were continuing to go (by bus) at the time of the study.

Sixty-one persons (61% of the study population) had received vocational rehabilitational services in the community, though not necessarily while in this board-and-care home. Of these, 18 persons had only seen a vocational rehabilitation counselor and a vocational plan had either not been offered or had been refused. Twenty-six persons had been placed in a sheltered workshop, a training program, or school but had dropped out. Three persons had

| Age, yr                   | Involvement (%) | No Involvement (%) | Total      |
|---------------------------|-----------------|--------------------|------------|
| <40                       | 40 (73)         | 15 (27)            | 55         |
| ≥40                       | 21 (46)         | 25 (54)            | 46         |
| <b>Total (P &lt; .01)</b> | <b>61</b>       | <b>40</b>          | <b>101</b> |

| Goals        | Age, yr*        |                 | Total      | History of Hospitalization† |                 | Total      |
|--------------|-----------------|-----------------|------------|-----------------------------|-----------------|------------|
|              | <30 (%)         | ≥30 (%)         |            | ≤6 mo (%)                   | >6 mo (%)       |            |
| Yes          | 13 (68)         | 35 (43)         | 48         | 23 (68)                     | 25 (37)         | 48         |
| No           | 6 (32)          | 47 (57)         | 53         | 11 (32)                     | 42 (63)         | 53         |
| <b>Total</b> | <b>19 (100)</b> | <b>82 (100)</b> | <b>101</b> | <b>34 (100)</b>             | <b>67 (100)</b> | <b>101</b> |

\*P < .05.

†P < .01.

been placed in a sheltered workshop or a training program and completed it; however, this had not led to sustained employment. One person had been placed in a sheltered workshop and then a training program and is currently employed. Eight persons are currently in a sheltered workshop and three are in vocational training or school. One had been placed by her vocational rehabilitation counselor in a job that she could not hold, and there had been no further contact as of the time of the study (three years later). Two persons had had sheltered employment in the past for two years or more but were currently unemployed.

Sixteen of those who had been offered or placed in sheltered workshops said that they had been unable to do the work or were fearful that they could not. Six persons thought that their vocational rehabilitation counselors had overestimated them and placed them in training programs beyond their capabilities; in two instances the training ended when the persons were hospitalized for psychotic decompensations.

Involvement with community vocational rehabilitation services (Table 3) is related to age; 73% of those younger than 40 years have had some involvement, compared with 46% of those 40 years and older.

Persons were considered to have goals if they expressed a desire to change *anything* in their lives, such as social or vocational activity or living situation, whether or not the achievement of these goals appeared to be realistic. Only psychotic goals (ie, starting a business buying and selling asteroids) were not counted. With the use of this definition, 48% had goals. There was a relationship between goals and both age and history of hospitalization (Table 4). Sixty-eight percent of those younger than 30 years have goals, compared with 43% of those 30 years and older. Sixty-eight percent of those with a lifetime history of hospitalization of six months or less have goals, compared with 37% with more than six months of hospitalization.

What do the residents say about how they experience their lives? The following classification was used to categorize their responses: predominantly dysphoric feelings

(45%), content or reasonably content (42%), and unable to classify because of the resident's retreat into fantasy and/or because his world is blurred by psychosis (13%).

### COMMENT

This study of all persons living in a board-and-care home has showed a population with predominantly psychotic diagnoses (92%). Almost a third (32%) manifest severe overt major psychopathology. Most of them receive their financial support from Supplemental Security Income. Though many have a tendency to drift in and out of board-and-care homes and from one to another, the median length of stay is 32 months and 42% have lived here continuously five years or more. Almost a third (31%) have been hospitalized during the past year; this is substantially higher for those younger than 30 years and is consistent with similar findings elsewhere.<sup>4</sup>

Nine of ten have either never tried living alone or had a failure experience the last time they tried. In talking at length with the individuals in this study, there was a consistent recounting of an inability to cope with social and vocational demands, an inability to withstand life's pressures, and a poverty of interpersonal relationships. A small minority (12) of persons in this study are particularly aware and insightful; they recognize that they become anxious and overwhelmed in social or vocational situations. With varying degrees of reluctance they have made a conscious decision to limit their exposure to pressure and in some cases to avoid pressure of any kind.

The persons in this environment have therefore come to what one might call adaptation by decompression. They have found a place of asylum from life's pressures but at the same time a place where there is support, structure, and some treatment, especially in the form of psychotropic medications. For a large proportion of long-term psychiatric patients, the board-and-care home has not only replaced but taken over the functions of the state hospital.

This particular board-and-care home provides structure in a variety of ways. Medication management and supervision is one way; two psychiatrists come to the facility and prescribe psychotropic drugs for the majority of the residents, and the staff members dispense these medications at regular times. The better members of the staff are reasonably aware of residents who are becoming symptomatic or more floridly symptomatic and convey this to the visiting psychiatrists, who then may adjust medications accordingly. In addition, the staff often sees problems that are causing the resident to be symptomatic and may intervene by manipulating the patient's environment to ease the pressures on him. There is additional structure in the supervision of the resident's money and disbursing it according to the staff's estimate of the resident's ability to handle his money. Frequently, the resident is overprotected by this, but there is flexibility and the staff generally tries to give residents as much responsibility as they can handle. The serving of meals at fixed times not only adds structure but ensures that the residents will eat on a regular basis. Many of the residents reported that when living alone their eating habits were erratic, often to the point of undermining their physical health and certainly their sense of well-being. Although having all one's

meals prepared may be more than some of the residents require, most of them have a feeling of being taken care of and of being relieved of a major responsibility.

It comes as no surprise that the board-and-care home is a protected setting. But despite the structure just described, the residents may have a great deal of freedom. For instance, in the facility where this study was done, everyone is free to come and go at any hour. Although 5% of the residents never leave the building, the other 95% use community resources to varying degrees, mostly by visiting local supermarkets and eating places and by taking walks in the neighborhood. Many, of course, probably could and should do more, and these persons might well be functioning at a higher level had social and vocational rehabilitation been made available early on and by persons skilled in working with residents with limited ego strength. But for those who cannot benefit from rehabilitation efforts, it may be that an inactive, sometimes even seclusive life-style in a pressureless setting may be the highest level at which they can function for any sustained period of time without decompensation.<sup>7</sup> It may be misleading to refer to these persons as "regressed" or "institutionalized"; one must first account for their incapacities and limitations.

### Some Problems of Board-and-Care Homes

In talking with residents and staff about their experiences in a number of board-and-care homes, another side of this picture emerged; some operators are seen as regarding their board-and-care homes almost solely as a business, squeezing excessive profits out of it at the expense of the residents. Whether or not this is true is far from clear, but having this situation overseen by a strong licensing and monitoring agency as well as patient advocate groups would do much to reassure staff, residents, and outside professionals. This applies to the physical structure, food, staff (both numbers and quality), and the provision of or arrangement for treatment and rehabilitation services. Segal and Aviram<sup>8</sup> suggest that certification of facilities with respect to the quality of the social environment be done by the professionals who place persons in board-and-care homes together with residents' groups. Most patients see themselves as dependent on board-and-care home operators and feel powerless to bring about a higher quality of care. Still another factor is the unwillingness of many residents to organize because of their reluctance to be identified with other mental patients.<sup>8</sup> There needs to be a striking of a balance so that the board-and-care home operators make a fair return on their investment and at the same time provide adequate service to the residents. There also needs to be more careful initial screening of the operators so that only the ethical and competent are allowed in.

There are other problems of board-and-care homes. The importance of cigarettes is prominent and many residents find annoying the constant request "to lend me a cigarette." Excessive drinking frequently gets out of hand and theft is a chronic problem. Competent staff and the fostering of an active resident government appears to lessen but not eradicate these problems for any sustained period of time.

### Facilitating the Use of the Program

The experience with the social rehabilitation program at this board-and-care home illustrates the importance of facilitating the residents' use of such programs. In the instance here, having the program nearby made a crucial difference for those residents who had chosen to use it. Possibly many of those who refused to attend even this program would have participated in a similar program had it been located in the facility. These findings have important implications for mental health planning. Simply enlarging existing clinics and rehabilitation facilities will not reach a large proportion of the board-and-care home population. It may well be that long-term patients who function well in community mental health centers and vocational rehabilitation centers are in the minority of the total population of such persons when we include those tucked away in board-and-care homes, those living alone, or those with their families.

Three fifths of the residents (and a substantially higher proportion of those younger than 40 years than those older than 40) had received community vocational rehabilitation services but with somewhat disappointing results. Only 12 of the 61 persons who had received services were still involved, one having been placed in competitive employment, three in a training program or school, and eight in sheltered workshops.

Some observations during this study may account, at least in part, for this outcome. One fourth of the residents who had received community vocational rehabilitation said that they had been unable to do the work in sheltered workshops or were fearful that they couldn't; the availability of prevocational services at a level at which these patients could function might well have made a difference.<sup>9</sup> With an additional 10%, the vocational rehabilitational counselors appeared to have overestimated their clients' strengths and placed them in training programs beyond their capabilities; in all these instances the failure experience seemed to contribute to the client's refusing to continue in vocational programs and/or the counselor's withdrawal from the case. In most cases, the vocational counselor had not been part of a therapeutic team that included a primary therapist or case manager.

Newly admitted residents in this study appeared to the author to be particularly receptive to involvement in treatment and rehabilitation programs. It would appear to be especially important to work with newly admitted residents while they can still be relatively easily motivated to participate in programs geared to their capabilities and before they have become too fixed in an inactive routine below their capabilities.

### Goals, Empty Lives, and Contentment

Half the persons (52%) living in this board-and-care home have no goals to change anything in their lives. And this lack of motivation is even greater in those older than 30 years of age and in those with a lifetime history of six months of hospitalization or more.

Although we have no data that will further interpret these findings, it is useful to speculate on some possible explanations. Perhaps persons with limited capabilities who are older have had more time to experience failure in

dealing with life's demands and in achieving their goals. Thus, they have had more time to lower or set aside their goals and to adjust to a life without goals and to a low level of functioning that does not exceed their capabilities.

With regard to the relationship between goals and history of hospitalization, perhaps those persons better able to deal with stress experience fewer failures and thus have both less need to be hospitalized at times of crisis and more reason to think that they can make changes in their lives. Still another possibility is that persons who have had less opportunity and need to experience the effects of a total institution such as a hospital have had less chance to experience the effects of institutionalism,<sup>10</sup> one of whose characteristics is a lack of goals.

The chronically disabled patients in the board-and-care homes observed in this study have feelings just like anyone else about not having goals, about not being able to reach their goals, about involuntal concerns, about getting old; this holds true not only for those in the involuntal group, but for those who are turning 30. Many feel that life has no meaning and are distressed by feelings of inadequacy. This may seem self-evident, and yet there is a tendency to forget that long-term patients are affected by the stresses and concerns of each phase of the life cycle, and that they have existential concerns just as do we all.

Many are acutely aware of their situations, their lives seem bleak and empty, and they are beset by depression and/or anxiety. A repeated theme was, "I'm just living day by day, waiting for the end." One man referred to being here as, "being at the bottom of the dumps." Perhaps some would benefit from better drug management. And surely this group should be the object of a concentrated effort at outreach from community agencies to provide individual and group psychotherapy and social and vocational rehabilitation. At the same time, it must also be recognized that there are persons in board-and-care homes just as there are persons in society generally for whom we do not have the answers with regard to making their lives happy, anxiety free, and meaningful.

Some persons retreat into fantasy or grandiose delusions to escape from or deny the reality of their lives. This may happen despite medications or because the patient refuses to take them.<sup>11</sup> Others are too disorganized to be fully aware of reality.

In this study, more than two fifths were considered by the investigator to be content or reasonably content. Probably, some of these persons were not living up to their full potential. And some observers would see their lives as empty and without meaning. For a number of residents, however, the board-and-care home has become an asylum after a lifetime of chaos, instability, and hardship. For one 44-year-old schizophrenic man, a lifetime of economic hardship, vocational failure, petty crime, and being in and out of jail and occasionally hospitals had preceded his coming to the board-and-care home two years before. His feeling of relief was evident and he seemed to have become stabilized and to be content. A 58-year-old schizophrenic woman had come to the board-and-care home at age 50 after a lifetime of prostitution, living on the streets, and intermittent hospitalization; she talked of a feeling of security she had never before experienced and she too

seemed content. The lives of a number of persons had in past years been characterized by many psychotic episodes and hospitalizations, each episode further disrupting their sense of psychological integrity and their interpersonal and family relationships. Many appeared to have become stabilized at the board-and-care home and their sense of relief seemed to predominate. Frequently, much denial and rationalization was necessary to achieve a relative feeling of contentment. For instance, one 37-year-old schizophrenic man who had graduated from college and had come from an achieving family had failed at everything he had ever tried. But he had rationalized his life as follows: in his fantasies he had achieved all of his goals. But after achieving them in his fantasies, he found them not as fulfilling as he had anticipated. There was even a sense of disappointment, he said, after he had in his fantasies realized all of his and his family's goals for him; he had anticipated a much greater sense of satisfaction. Therefore, he knew that reaching these goals in real life was not really worth it. And looking at it this way, he felt reasonably content with his life of reading, taking walks, and keeping up with world affairs.

Persons who have experienced board-and-care homes from the inside have stressed the importance of helping these long-term patients keep their respect and dignity.<sup>12,13</sup> Many of the residents in this study appeared reluctant to

make negative comments about the board-and-care home or the staff. But some spoke freely about both the positives and negatives of the board-and-care home studied here and of the other board-and-care homes where they had lived. What emerged was an impression of their sensitivity to the way they are treated, both good and bad. To quote one of the more aware patients who had recently come from a board-and-care home now closed by the state licensing agency, "If you are housed in a dilapidated, poorly maintained building, fed poor-quality food, and treated impersonally by the staff, you cannot help but feel that you aren't worth much, for otherwise you would not be treated that way." It does immeasurable damage to the residents' self-esteem to be served their meals an hour late by kitchen staff who do not seem to care, to find no one on the staff who seems to appreciate the importance to the residents of the "little things" of everyday living, and to be abruptly turned away and rebuffed when they make what to them is an important request. For some of the chronically mentally disabled, a board-and-care home or similar facility may be a lifetime residence. Our society has a commitment to provide them services, improve the quality of their lives, and help them gain a sense of self-respect.

#### Nonproprietary Name and Trademarks of Drug

Lithium carbonate—*Eskalith*, *Lithane*, *Lithotabs*, *Pfi-Lithium*.

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