BETWEEN ASYLUM AND INDEPENDENCE:

Toward a System of Community Care
for People with Long-Term Mental Illness

BY

ELIZABETH T. MURPHY

B.A.   College of the Holy Cross

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C   Elizabeth T. Murphy   1988

Signature of the Author_____
Department of Urban Studies and Planning
May 6, 1988

Certified by_____
Langley C. Keyes
Professor, City and Regional Planning
Thesis Supervisor

Accepted by_____
Donald A. Schon
Director, Master of City Planning Program

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ABSTRACT

Residents and staff in four group homes for the long-term
mentally ill were interviewed about the benefits and problems
of group home life. In addition, administrators in agencies
that operated community residences, Massachusetts Department of
Mental Health officials, and other state officials involved in
planning for mental health housing, were also interviewed.
Their comments and opinions provided the basis for a
description of how the resident lives within the group home,
and how the group home operates within the state mental health
system.

The results of this study indicated the need to reorganize the
state mental health system around an effective system of case
management, in order to improve community-based mental health
services. This reorganization would have a positive impact on
group home life, and on the long-term mentally ill resident's
life in other types of community residences as well.

INTRODUCTION

The mental health services system in the United States has
undergone many changes over the last thirty years. In 1955,
the state hospitals in the United States housed 559,000
patients.(1) With the widespread use of psychotropic medication
in the 1950´s, the state hospital inpatient census began to
decline precipitously.(2)   The enactment of Federal
legislation in the 1960´s, which allowed states to shift the
cost of caring for non-hospitalized psychiatric patients to the
Federal government, and a series of court decisions in the
1970´s upholding the civil rights of state mental hospital
patients, contributed to a further sharp decline in the state
hospitals´ inpatient census, until in 1980 there were 138,000
patients in state hospitals across the United States.(3)(4)
This rapid emptying of the state hospitals became known as
deinstitutionalization.

The course of deinstitutionalization in Massachusetts
parallelled the process that took place in the rest of the
nation. In 1960, Massachusetts had eleven state hospitals with
a total census of over 20,000 patients. In 1985, seven state
hospitals remained with a combined inpatient census of
2,400.(5)

Where did these deinstitutionalized patients go and where do people with long-term mental illness live today, if not in state hospitals? One study found that of the patients released in the first wave of deinstitutionalization, approximately 70-80% returned to their families, while the remainder lived alone or in boarding houses.(6) This finding indicates that the first wave of ex-state hospital patients were more easily assimilated into the community than patients released subsequently. Greater availability of low income rental units in the late 1950's and early 1960's, and the release of the least disturbed patients first, are factors which probably contributed to their assimilation.

More recent data from 1977 indicates that approximately half of all chronically mentally ill people live in the community: with family, in various types of community residences designed to serve the mentally ill, or in boarding homes, hotels, or other low income rental units. The other half of the chronically mentally ill population resides in institutions, primarily nursing homes. (7)

The character of institutional life for long-term mentally ill people has been exhaustively studied and widely discredited. The deleterious effects of institutional isolation, depersonalization, and regimentation on the long-term mentally ill person's ability to function and sense of self-esteem are

well documented. (8)

Yet the aspects of life in the community that contribute to improved functioning and/or heightened self-esteem for the long-term mentally ill person are not well understood. In contrast to the former state hospital system's one-size-fits-all approach to the treatment of long-term mental illness, the care and treatment of long-term mentally ill people in the community is characterized by diversity.

Community settings range from the long-term mentally ill person's family of origin, to foster care, to group homes, to single room occupancies, to supervised apartments, to board and care facilities. Programs operated within these settings run the gamut from high expectation to low expectation to virtually no expectation. Clients range from young to old, from mildly to actively psychotic, from having spent many years in institutions to having spent none. Most importantly, some long-term mentally ill people thrive in each of these types of settings and programs, while others suffer as much, if not more, as they did when they lived in institutions. Budson, citing Carpenter's review of 60 evaluative studies of community residential care, concurrs with his judgement that, "little is known... about the factors which contribute to the success or failure of these community residences." (9)

To understand this diversity in community residential care it is necessary to "go back to the things themselves", to look at community residences from the point of view of those who live and work in them, the long-term mentally ill residents and the staff. From this vantage point, we can see what things make life in the community better than life in an institution for the long-term mentally ill person and what kind of problems make it hard for him/her to stay in the community. We can also begin to understand the role that staff people play in enabling long-term mentally ill people to stay in the community, and see how that role is supported or discouraged by the organization of the mental health service system of which the community residence is a part. By noting the divergence of opinion between staff and residents, and between staff and the mental health service system, we can begin to construct a more accurate picture of how the community residence works in practice, and how these differing viewpoints might be reconciled to make it work better.

For this thesis, I chose to look at one particular type of community residence: group homes. There are two opposing views of group homes that I wished to examine. One is that group homes are most appropriate for severely disturbed, long-term mentally ill people. In this view, the structured activities of group home life, and the constant staff presence help instituionalized or highly thought disordered residents to cope

with living in the community. Currently, DMH is pursuing

housing development plans based on this view. (10)

The other view is that group homes are less likely to promote

the rehabilitation and community integration of residents than

would more normal housing situations, such as living in an

apartment alone or with a roomate. Proponents of this view

contend that even severely, disturbed long-term mentally ill

clients are more likely, with the proper configuration of

supports, to achieve higher functioning in normal housing than

they would in a specialized facility such as a group home.

According to Carling and Ridgway, "Normal community housing is

preferable to environments organized for the sole use of groups

of people with psychiatric disabilities. Natural support

systems are most easily fostered in normal housing." (11)

Both these views leave many questions unanswered about how a

group home functions, either to the benefit or detriment of its

residents. Both fail to specify how the unique needs of the

severely, disturbed long-term mentally ill population are

better served by either specialized or normal housing

respectively.

This thesis looks at how a group home functions according to

the staff and residents who work and live in it. It is an

inquiry into the relationship between them, and how that

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relationship enables the long-term mentally ill person to live in the community more comfortably or more productively than they would have in normal housing.

This thesis also examines the concepts of rehabilitation and disability as they relate to long-term mental illness and as they manifest themselves in everyday life in the group home. In what ways is long-term mental illness disabling? What is it about the disability that makes group home living "therapeutic" for the resident, and how "rehabilitated" are residents expected to become? Of equal importance, where does the disability end and the normal frustrations and disappointments of everyday life begin? By developing a greater understanding of the disability of long-term mental illness in the context of everyday life in the group home this thesis should contibute to a more specific definition of the kinds of rehabilitation outcomes we should expect from residential care.

As Lamb points out, "There are many different kinds of long-term patients and they vary greatly in the degree to which they can be rehabilitated. Patients vary widely in their ability to cope with stress without decompensating and developing psychotic symptoms, and they differ in the kinds of stress and pressure they can handle....Thus, for a sizable majority of long-term patients, rehabilitation in terms of competitive employment, high levels of social functioning, and return to

the mainstream may not be a realistic goal." (12)

Contrary to the normalization view, mainstreaming is not always the answer for people who because of their disabilities, their race or gender, do not conform to the social norms of the dominant society.

There is a long and respected tradition of "sheltered" institutions where members of disenfranchised groups can go to develop their abilities, sheltered from the demands, exingencies and criticism of mainstream society. Colleges begun exclusively for women and blacks are one example. Research shows that students of these schools often emerge more capable of competing in mainstream society, having developed their abilities and self confidence to a greater degree in the more accepting, specialized, sheltered environment of these colleges than they might have if they had attended mainstream institutions.

Galudet College for the hearing impaired is another example of a specialized institution that allows disabled people to develop their potential to a much greater degree than would have been possible in a mainstream institution.

These examples highlight the potential of sheltered environments to allow long-term mentally ill people to develop

in their own way, at their own pace and with the affirmation that they are worthwhile people even before they are "rehabilitated". As a house manager replied when I asked her what about her job was rewarding: "It's rewarding to know that there can be places like this."

It is crucial to understand, however, the difference between a sheltered environment and exclusion. With a sheltered environment, the subgroup decides to live and work separately so as to be better able to develop themselves. With exclusion, the subgroup is forced to live a marginal existance on the edge of mainstream society. The difference is one of choice. The difference is also one of money.

A sheltered environment and client choice of housing options are not incompatible provided that normal housing is also available to the client, and the client is given the information and encouragement necessary to participate in his/her housing decision. Even after a client has chosen to live in a sheltered environment such as a group home, the client should continue to be encouraged to make choices in matters large and small whenever possible.

As we shall see in the following chapter, all the group homes in this thesis were philosophically committed to resident choice, but in many instances felt unable to put that

commitment into practice. A big part of the problem for group

homes is simply underfunding: not enough staff to provide

individual attention to the residents, not enough money in the

group home budget to do routine maintainence and repair on the

residence, or to hire relief staff. Group homes should not be

viewed as a cheaper alternative to normal housing. Low levels

of funding inevitably turn a sheltered environment into an

impoverished and custodial one.

Method

I picked four group homes in Eastern Massachusetts, that were

funded by the Massachusett's Department of Mental Health (DMH),

and operated by a private mental health services agency under

contract to DMH. These agencies are called vendors. Most

community residence programs for long-term mentally ill people

in Massachusetts are run by vendors under contract to DMH.

My study of these group homes consisted of interviewing staff

and residents in each home. The questions I asked in these

interviews were fairly open-ended. I asked staff questions

such as: What do you like about working here? What don't you

like? What are the sources of stress in your job? What are

the rewards? How do you deal with crises? I would follow up

on remarks that staff made that seemed surprising,

contradictory, emotionally charged or just obscure.

During the second half of the interview with a staff person, I would ususally introduce an opinion expressed in the literature, or a point made by staff or administrators from other residences, and ask for the staff person's comments on it. Sometimes the point I raised would seem insignificant or irrelevant to the staff person I was interviewing, sometimes it would spark a lengthy response or a vivid story that would illustrate the staff person's own views. In either case, I would follow the staff persons lead and let him/her talk about the issues that seemed most important to him/her. Interviews with staff lasted anywhere from a half hour to an hour and a half, with most interviews taking about an hour.

Resident interviews tended to be much shorter, taking from fifteen to forty-five minutes. Out of a possible 38 residents, 9 agreed to be interviewed, while 13 out of 23 staff members agreed to interviews. The lower rate of resident participation was probably due to residents finding interview situations to be overly stressful or intrusive. Of the residents who did participate, most seemed fairly comfortable with the interview situation, and some seemed glad to be asked their opinion. On my third visit to one of the group homes, a resident said to me, "I enjoyed talking with you the other day." Only one resident appeared agitated during the interview and she ended it after fifteen minutes.

The questions I asked residents were also open ended. What do you like about living here? What don't you like? What would you change about the house? Where would you like to live ideally? As with the staff, I followed the resident's lead and let him/her determine the pace and content of the interview, dropping topics that seemed uninteresting or uncomfortable to them. Much more so than in my interviews with staff, I was careful to avoid probing questions. Instead, I relied on the information they were willing to volunteer about their housing situation.
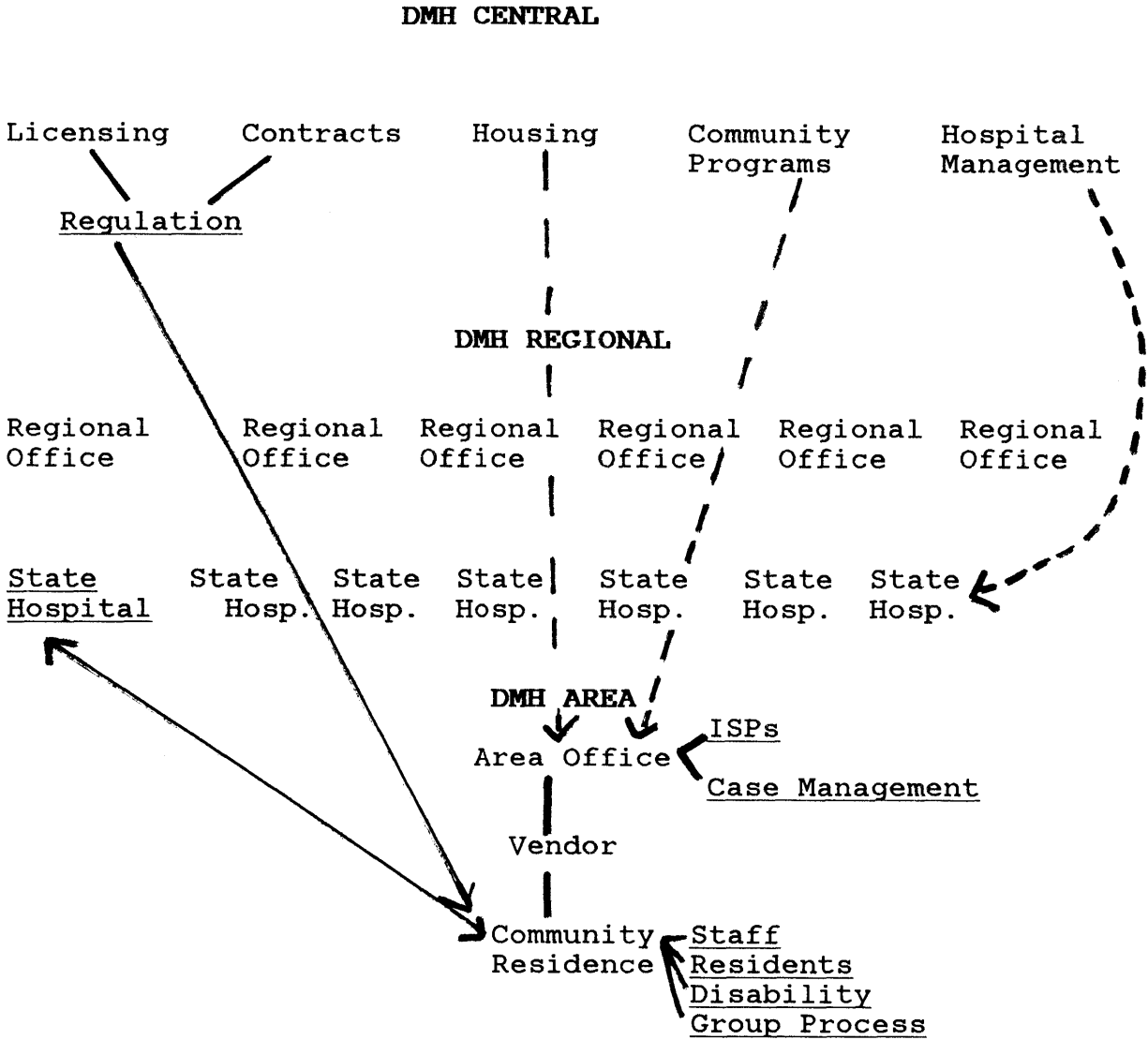
To get more information on where group homes fit in to the mental health service system, I also conducted interviews with vendor administrators, DMH Area Office personnel, researchers on community residences, a therapist in a privately funded residence, family members of mentally ill people, DMH Central Office staff, and personnel in various other state agencies involved in devloping housing for long-term mentally ill people. (see Appendix 1)

In these interviews, I asked questions about issues staff and residents had raised, as well as asking for the interviewee's opinion of how the community residential system works now, and how it should operate in the future. The purpose of these interviews was to contrast how a group home runs according to the staff and residents who work and live there, with how

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others involved in shaping the mental health service system see the functions of a group home. A great disparity between the internal and external views of how a group home functions indicates tensions and contradictions within the mental health service system that could undermine the implementation of any housing plans for long-term mentally ill people. Any housing plan which ignore the needs, desires, and actual behaviors of its intended recipients is more than likely to fail.

Organization of Thesis

The following chart illustrates the organizational relationship between DMH and the vendors who run community residences:

DMH CENTRAL

Licensing   Contracts   Housing   Community   Hospital
                                              Programs   Management

Regulation

DMH REGIONAL

Regional   Regional   Regional   Regional   Regional   Regional
Office   Office   Office   Office   Office   Office

State   State   State   State   State   State   State
Hospital   Hosp.   Hosp.   Hosp.   Hosp.   Hosp.   Hosp.

DMH AREA

                                    ISPs
Area Office
                                    Case Management

Vendor

Community   Staff
Residence   Residents
              Disability
              Group Process

This thesis is organized to describe the internal functioning of the group home in Chapter One and its relationship to the state mental health system in Chapter Two. The relationship

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between staff and rsidents, the disability as it is understood within the group home, and the relationship between the individual and the group are all described in Chapter One.

Chapter Two describes how the various levels of the state mental health system (DMH) interact with the group home. The state hospital has the most direct impact on the group home as that's where many group home clients come from and return to in times of crisis. Next DMH Central is responsible for setting overall policy toward the group home and for monitoring the quality of community residences. Finally, the Area Office has the most frequent contact with the group homes and is responsible for monitoring the residents individual service plan (ISP) and for providing case management services to some of the residents.

The Area Office and the State Hospital are officially under the direction of DMH Central but due to the size of the service system, its uneven development from Area to Area, and a history of alternately centralizing and decentralizing power within the organization, DMH Central's control over policy and procedures varies greatly from Area to Area. DMH has the largest budget of any state agency, and is the largest employer, public or private, within the state. The relationships among the various components of the state mental health service system, and between the state mental health service system and the group

home, can be better understood if these facts about DMH are
kept in mind.

Chapter One

LIFE IN THE GROUP HOME

"Experiencing the impersonal bigness [of state mental
hospitals] and the isolated smallness [of nuclear family
life] as a sign of society's decay, and a detriment to the
rehabilitation of the mentally ill, small groups of workers
began, largely on their own, to develop in different
locations across America the first psychiatric halfway
houses. Very often these community residential facilities
began as experiments defined as much by antiestablishment
tone as by common programatic factors.

...About the deficits of the traditional large public
psychiatric hospital there was considerable agreement:they
were too large, were limited by a universal medical model,
and functioned as a closed society - isolated like a
penitentary, from society at large. Community residences,
by contrast, were to be small, family-modeled living
arrangements, functioning as open social systems, which
existed within rather than isolated from the community.
(13)

The psychiatric halfway house model developed and proliferated

in the 1960's and early 1970's. What began as an

"antiestablishment" movement to reclaim psychiatric patients

from the state hospital, was soon adopted by the state mental

health system as a housing model. There were other community

residence models in existence at the time. Two of them were

the Fairweather Lodge model and the Veterans Administrations

use of foster care. The Fairweather Lodge model combined

vocational and residential rehabilitation by having clients

live together and own and operate a business together. The

Veteran's Administration relied extensively on fostercare to

house many long-term mentally ill veterans.   Neither of these

models caught on at the state level. *

The halfway house model was based on the concept of therapeutic

community.   Through living with other ex-patients and staff,

the resident would learn to interact comfortably with others in

a social situations.   Residents would also learn to share

responsibility for chores like cooking, cleaning and grocery

shopping.   The resident was supposed to be motivated toward

positive change by his/her acceptance in and identification

with the group.   The ultimate goal was that the resident would

be able to internalize that self acceptance and responsibility

and move on to take his/her place in the larger community.

THe original halfway house model has been modified and refined

over the years.   The "antiestablishment tone" of staff has

been replaced by an emphasis on structured activities geared

toward resident rehabilitation.   The family like aspects of

living with a group have been downplayed.   Vocational

rehabilitation and dayprograms have been added as necessary

support services for the community residence.

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* The reason why the Fairweather Lodge model didn´t catch on at
the state level is likely to have been that it was more
difficult and time consuming to organize than halfway houses.
The Veterans Administration was able to use the foster care
model successfully because they were able to pay, based on the
veterans´ disability pensions, foster parents two to three
times the amount that the state could based on clients SSI
income.

Finally, the idea of transition within a short or specifiable period of time has been largely abandoned by community residence staff. A resident must be both willing and able before they are asked to consider moving on. The result of these modifications to the halfway house model is the group home as it typically operates today in Massachusetts.

Group homes are a radical departure from the typical housing pattern of most adults in the community. It is highly unusual for 8 to 12 adults to share a house and domestic activites such as cooking, cleaning and grocery shopping. Communes, congregate housing for the elderly, halfway houses for ex-offenders and alcoholics, and group homes for the disabled, are the obvious exceptions to the typical pattern of housing use in the community.

Background

Though the group homes I visited were unique in many ways, they had in common an orientation toward structured rehabilitation activities, a view of staff as mental health professionals, a connection to other mental health services such as vocational workshops and dayprograms, and a view of the group home as the resident's home and not as a transitional treatment facility.

The staff who worked in these group homes came from a variety of backgrounds. Several staff people came directly from

college and were working in the group home to get experience in working with mentally ill people before pursuing graduate work in psychology. Several had worked in other human service activities before such as counselor on a crisis hotline, and day care provider. Some had come from completely unrelated jobs such as mail carrier. Surprisingly, several staff members had come from higher paying, unrelated fields such as computer science and personnel, and had taken significant pay cuts to work in the group home. At the other end of the scale, house managers reported hiring people with their own psychological problems or substance abuse problem as well as people with marginal work histories.

Three out of the four group homes in this study reported being chronically understaffed: having positions go unfilled for months at a time and being unable to find and/or fund relief staff.

Staff age and length of time on the job also varied widely. Of the thirteen staff interviewed, there were four in their early twenties. Time on the job for this group ranged from five to nine months. There were five other staff who ranged in age from the mid-twenties to the mid-thirties, and had been on the job from six months to a year and a half. Finally, there were the four house managers who were in the late-twenties to late thirties age range, and who had been on the job from three to

seven years having started out as a staff person in a group
home and stayed with the vendor agency

Staffing patterns also varied considerably among the four group
homes in this study. The breakdown was as follows:

	# Staff	# Residents
Group Home A	9	10
Group Home B	5	12
Group Home C	3	8
Group Home D	6	8

These staff provided twenty four hour coverage seven days a
week, except for Group Home C which had relief staff cover the
weekend.

Residents in Group Home A came primarily from the state
hospital. There were five men and five women ranging in age
from twenty nine to sixty. Residents ran the range from high
functioning to low functioning, and had a variety of diagnoses:
bipolar disorder, schizophrenia, borderline personality, etc.

Residents in Group Home B had come from another group home and
a supervised apartment which the vendor had operated and
decided to close. All had originally come from the state
hospital. The majority of residents were men in their thirties
through fifties. They had a range of functional assessments

and diagnoses.

Group Home C residents came primarily from the community from private psychiatric hospitals and other community residences. A few residents came from the state hospital. The age range was from 18-35. Most of the clients were higher functioning with the exception of one dual diagnosed MR/MH client.

Two out of the eight residents in Group Home D came directly from the community. The rest were from the state hospital. There were three dual diagnosed MR/MH clients in this home. Clients ranged in age from twenty to sixty. The house was considered the lowest functioning group home in a residential continuum of four community residences.

Organization of Chapter One

This chapter looks at the relationship between staff and residents, the concept of the disability of long-term mental illness that is used in the group homes, and how group process interacts with the disability to the benefit or detriment of the resident.

Section 1.1 The Staff, looks at the dilemma that group home staff face in trying to develop a relationship to long-term mentally ill residents that meets the residents many social and emotional needs. Staff experience a lot of self doubt about

where to set the limits in their relationships to the long-term mentally ill residents. They are often called on to play the contradictory roles of therapist, parent, and friend, and feel that the extent and intensity of the residents' social and emotional needs preclude giving up any of these roles. Section 1.1 explores this limit setting dilemma.

In section 1.2 The Residents, residents of the group homes express their opinions of group home life and their relationship to staff. They talk about where they have lived in the past and where they would ideally like to live in the future. The problem of "screening", whereby most of residents' interactions with the community are mediated by group home staff, is discussed.

Section 1.3 The Disability, looks at the disability in the context of the residents' everyday life in the group home. It discusses how staff view the disability and how they approach rehabilitation.

Section 1.4 Group Process looks at many different aspects of group process: group size; how group meetings are used to enable residents to air emotions and participate in decision making; the tension between group and individual needs. The lack of clarity around which clients are appropriate for group home living is also discussed

1.1 The Staff

A Federal Aviation official once described an airline pilot's job as "hours of boredom punctuated by moments of terror". He was referring to the life and death responsibility of the pilot to handle difficult take-off and landing procedures in contrast to the repititious and uneventful hours of flight. Lengthen the time frame a little, and he could have just as easily been describing the job of a staff person in a group home.

The bulk of a staff person's job consists of trying to motivate people who lack motivation on the one hand, and on the other, trying to control people who's behavior is disruptive or destructive. They must push the clients, as a group, through the daily routines of getting up, getting out, making dinner, cleaning up and going to bed. At the same time staff must be attuned to the warning signals of any one resident heading for a crisis. Amidst the ongoing struggle to get residents to attend to the normal routines of daily life, staff must remain aware of the resident's extreme vulnerability to stress, such that seemingly innocuous incidents, interactions or requests can trigger a state of emotional turmoil in the resident. Staff can go for days, weeks or even months just handling the mundane and repititous tasks of helping residents structure their day, then suddenly be confronted with the "moments of

terror" of talking down a client who is actively suicidal, threatening or violent.

The job of a staff person in a group home is "overwired" for burnout. Over and above the usual stresses and strains which most social workers involved in trying to help multi-problem clients feel, staff in group homes are regularly frustrated by the contradictory demands of the role they are required to play. Their job is framed by paradoxical directives: treat the resident as an adult but control him/her; form a caring relationship but don't become involved; live with the residents but keep your distance; be prepared to handle a psychotic episode and still get dinner on the table; in short, try to make the abnormal seem normal. Burnout - the point where the staff person gives up on the residents, or gets out to avoid giving up - is the inevitable result of a work situation in which the staff person is expected to be all things to the residents.(14)

Is it worth it? Is the stress and the heartache which staff experience in trying to enable long-term mentally ill residents to stay in the community worth the little bit of progress that some residents make? Is it worth it to the resident to try to learn how to take part in social interaction when social interaction can unleash powerful feelings of self-hate and despair? These questions underscore the doubts that many of

A staff person at another residence began confidently

explaining to me the benefits of their program for the client.

Midway through her explanation, she began to express some

doubts.

> "For me its rewarding to see that I can be an effective
> caregiver, that I can forge alliances with the residents.
> I don't see people getting better. The rewards of this job
> are much more subtle than that - like seeing a client who
> just moved in become adjusted. Or to see someone like
> Joanne, who is actively psychotic, to see her have a nice
> night instead of seeing her crying and anxious as usual.
> Just to see her enjoying herself for one evening is
> rewarding.

> Even as I'm saying this to you I feel my own dissatisfaction
> creeping in. It's just so hard to go on seeing the same
> problems repeat themselves month after month, to see people
> struggling with the same problems over and over again. I
> find it very hard to feel satisfied with one good evening
> for Joanne."

Much later in the same interview, this staff person described

more fully her sense of doubt about the worth of her treatment

approach to clients. Her comments illustrate that this sense

of doubt is not just a momentary lapse in confidence, but an

ongoing source of stress and tension in her job:

> "I have a friend who works at a womens' shelter. They have
> a very different philosophy there. They don't think of
> themselves as doing treatment. They think of themselves as
> keeping the place running so women can have shelter. My
> friend is just supposed to be herself and get the task at
> hand done.

> Yet, when we talk about our jobs we have the same kind of
> feeling about the different roles we play. The same sort of
> getting involved occurs. We both get caught up in what the
> residents' lives are about. We have the same feeling of
> futility and stress in trying to help people who's lives
> have really gone awry. And we also share that sense that
> most people don't understand what kind of job you're doing

the group home staff that I interviewed feel about their role in enabling long-term mentally ill clients to stay in the community. At the same time that staff express confidence in the overall treatment goals of the residential program, they also express doubts about how much good they are doing for any particular client, and at what emotional cost to the client and themselves.

Staffs´ doubts about their own efficacy, and about the usefulness of the treatment philosophy espoused by their own residential program, were brought up by almost all of the staff people interviewed. Sometimes these doubts were raised as an aside to another point the staff person was making. The following quote is an example of this:

> "Most of our clients have been abused - sexually, physically, emotionally. They´ve been laughed at and ridiculed by "normal" people. We treat them with respect. I think that makes a difference to them. That´s what I believe in spite of the times that clients verbally attack me. Maybe I need to believe that or otherwise I couldn´t keep working here."

Another staff person was more direct in expressing skepticism about the espoused treatment philosophy of her residential program, and its usefulness in helping her deal effectively with residents:

> "I sort of find the whole psychiatric rehabilitation model useless. It all sounds so good in training and I always feel inspired when I leave there, but it just doesn´t carry over into what I do around here day after day."

and why you´re doing it.

Here, in this residence, staff are always saying maybe we shouldn´t get so involved with the residents. There, at the shelter, they say `Maybe we shouldn´t be so distant and sit back and let them ruin their lives.´ Either way staff are frustrated and either way it seems about as many clients make it."

She ended the interview by saying:

"I can really be down on this job one day and another day I can be really positive. On a good day I love the job and on a bad day I´m ready to quit. My perception is really colored a lot by how that day is going. I know from talking to other staff here that they also have these constant swings in feelings about the job. Maybe because we´re dealing with clients who´s mood swings so rapidly. One day the client´s doing great and you think they´re on their way. The next day they can be in a devastating crisis. Even staff who have been here a long time don´t seem to hit equilibrium."

Why is it that staff people don´t reach equilibrium? Staff´s doubts about how they should do their job seem to go from one extreme to the other. They wonder whether they are doing enough, given the suffering they see residents go through. As the staff person quoted above said, " It´s hard to be satisfied with one good night for Joanne." At the other extreme, staff wonder if they are doing too much. Staff experience a lot of self-doubt around the issue of limit setting.

Limit setting is a particularly difficult issue for staff dealing with long-term mentally ill clients because of the rapidly fluctuating nature of the client´s disability. At

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times, the client is perfectly capable of making a rational, adult decision and should be allowed to do so. At other times, the client may be so disengaged from reality as to need an authoritative guide to help him/her negotiate their way through the real world. And their are other times when the client is just plain manipulative, egocentric or impulsive.

One of the costs of long-term mental illness is that many clients miss developmental milestones during adolescence and young adulthood, as all their time and energy is consumed in struggling with the disease. As a result, many severely mentally ill persons never had the chance to develop basic social and interpersonal skills.

The different levels of functional ability outlined above, may appear in the same client in rapid succession, leaving staff unsure of who they are dealing with: the rational adult, the disoriented person, or the manipulative adolescent. The rapid fluctuation of functional levels in the client call for an equally rapid switching of roles in the staff person. Staff must decide whether they should respond as a peer, a therapist, or a parent. It is easy for staff to miss their cue, causing resentment in the client and more self-doubt in the staff person.

The following quotes illustrate staff's predicament in trying to judge which role they are called on to play:

"My experience in working with severely retarded people gave
me a headstart on being comfortable with limit setting.
Some of the other new staff, I think, experience more
difficulty with that. I've had to learn more about limit
setting in a verbal way, as opposed to the kind of
structural limit setting I used to do with the mentally
retarded people I worked with. My experience with retarded
clients showed me why it is important to be able to set
limits on people for their own safety and well being.

Here its more difficult to see when limit setting is helpful
and when its just restrictive. For example, if someone is
cursing, are they just blowing off steam? Are they
threatening another resident, or are they being disruptive
to the community? You have to decide which it is and how
you should intervene. I find I do a lot more second
guessing of my interventions here than I did with working
with the mentally retarded."

Another staff person also brought up the problem of limit

setting:

"My job stress comes from being live-in. I get too
personally involved. It's hard to separate my on-time from
my off-time. Especially for me, I get drawn into clients
emotional problems and want to help them, and then they turn
on me and verbally attack me.

It's hard to play the professional when you live here. This
job used to be more of a hanging-out, just be-with-the-
people type situation. They used to call my job milieu
worker. Now I'm supposed to be a limit setter. It's hard
for me and for the clients to adjust when I go in and out of
that kind of authoritative role."

Another staff person describes the limit setting dilemma in

detail:

"The biggest issue is keeping the boundaries in your
relationships with the clients. One minute you're acting
like a therapist, the next you're having a cigarette with
them, or mopping the toilet in the bathroom with them, or
cooking dinner with them. I mean these people see me get up
in the morning after an overnight, with my hair messed up
and staggering for my first cup of coffee in the morning.

The boundaries are so hard to keep.

Its a dilemma because you can't give up the therapist role.
People here are too needy for that. A good example of this
dilemma is I'll be cooking dinner with a client and they'll
start talking to their voices. I can deal with that a
couple of ways. I can respond by setting social limits on
inappropriate behavior - in other words, trying to get them
to ignore the voices for a while and finish cooking dinner.
Or I can act like a therapist and go over with them what's
bringing on the voices, how do the voices make them feel,
how can we control them? Which way I respond depends on the
situation. There's a lot of sudden switching of gears
between the therapist's role and the social role model
role."

Another staff person put the problem and its solution quite

succinctly:

"Periodically, residents will have boundary issues. They
get confused as to whether the staff person is a friend or a
professional. We take a firm stand that staff are not
friends. They care and want to help but they are staff. I
think residents experience disappointment or maybe feel some
rejection, but ultimately they feel safer with staff that
will maintain that distance."

A few minutes later, this staff person added:

"It's hard to know how hard to push someone. It varies from
person to person. I have a tendency to want to be
nurturing, to do things for them. I have to check myself."

Another staff person also responded quite confidently about how

to resolve the dilemma of limit setting:

"I think to work here you have to have "tough love". You
have to be able to set limits, but you have to be able to
feel affection for people. You can't do this job if you
don't. The trick is to set limits and have them know you
still like them. You have to be understanding and firm at
the same time. Clients always throw back at us that we're
being mean. We're not friendly. I always say `I'm not your
friend. I'm not here to be your friend. I'm here to help

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you learn skills.´ Everything here is learned by constant
repetition."

By chance, I witnessed this staff person's version of "tough
love" in action. During our interview a client came in quite
upset. It seems the client had gotten into trouble on the job
and her supervisor had called the house and spoken with the
staff person I was presently interviewing.

The staff person said to the client, " I got a call from Nancy,
your supervisor. We can discuss what she said to me after
you´ve had your dinner and done your chore."

At this point, the client burst into tears, saying, " I know
what she said, so I´m in trouble now. Everythings a mess and
I´m in trouble now."

The staff person responded firmly, "No, that´s not what she
called about. We will talk about it later."

The client only became more agitated. "Oh I´m in trouble now
and its not my fault." She began crying inconsolably.

The staff person´s tone softened, but she kept repeating, "Go
do your chore now and we will talk about it later. I want you
to go upstairs and vacuum and I will be up in 15 minutes to

talk to you."

I was impressed by the staff person's ability to do exactly what she said should be done in a situation like this, and to do it under very trying conditions: with an interviewer present, with an agitated client, and with other clients arriving back from their workshops and day programs in various states of distress and disarray. I was also touched by the fact that the woman was clearly moved by the client's anguish, but was able to remain firm and calm.

The interview concluded and the staff person left to talk to the client as she promised. I proceeded to interview other staff and clients. As I was packing up my notebooks to leave, the staff person returned from talking to the client. She touched me on the sleeve and said in a conspiratorial undertone, "You asked me in the interview what the sources of stress were in my job." She paused and made a gesture to indicate all the emotional ups and downs I had witnessed in the short space of time I'd been at the house, and then she said, definitively, "Burnout."

Clearly, the "switching of gears", being tough but loving, deciding when to let up and when to be demanding, when to get someone to "just cook dinner", and when to stop cooking dinner and explore the emotional chaos someone is experiencing, all

take a tremendous amount of emotional energy from staff. Even staff who feel they've resolved the dilemma by saying, "We're not friends, we're staff", still experience the emotional strain of trying, under conditions of uncertainty, to do the "right thing" for clients they like very much and want to help.

Staff in community residences are less able to take their mistakes in stride than are other human service professionals. Any error in "professional" judgement usually has an immediate, visible and sometimes profound impact on someone they care about, and thus on themselves as well. Simply stated, professional distance is hard to achieve when one is intimately involved with one's clients. There are few professionals who literally take their clients home with them. Even though most staff do not live-in, they all cook, clean, eat, sleep, dress and socialize in the community residence. Under these conditions, professional distance is necessarily eroded.

Yet, staff raise valid points about their need to maintain some professional distance in order to a) help the client, and b) protect themselves. As one of the staff people previously quoted put it, "...ultimately, they (clients) feel safer with staff that will maintain that distance."

The prospect of friendship with a staff person raises the frightening possiblity for the client that the staff person

will be unwilling or unable to control them when they are in a psychotic phase. The reciprocal responsibilities of friendship mean the client may be held accountable for controlling him or herself. This is a responsibility that many long-term mentally ill people can only accept sporadically. For this reason, the burden of responsibility, and thus of control must remain with the staff.

Moreover, staff need to protect themselves from abuse by clients and professional distance is a way to do that. If many of the things clients say to staff were taken at face value, or taken to heart, staff would feel degraded and hateful toward clients. When staff are able to rationalize client's abuse in terms of the client's underlying emotional state, they are able to work with the clients in dealing with that emotional state, instead of defending themselves and leaving the client to deal with their own emotional problems.

This notion of dealing with the underlying emotional state contradicts the normalization ideal which promotes helping clients practice behaviors in real-world situations. In the real world, if a client began taunting someone and calling them names, the person might respond in kind, or might simply have nothing more to do with the client because they thought the client was just an unpleasant, nasty sort of person. It is, however, precisely the "unreal world" quality of community

residences which makes them safe places for clients with long-term mental illness to be.

A therapist in a privately run community residence explained that this "unreal world" quality was a vital component of the treatment provided in a community residence:

> "Mentally ill people are very socially isolated. For one thing, they're in a lot of pain and pain isn't socially acceptable. Other people feel threatened by how much pain they are in. So there are very few places in society where people will even listen to whats going on with a mentally ill person. They don't have the time or the patience for it.
>
> Here in the residence, we create a smaller society where people have the time and the interest to listen and to help mentally ill people learn how to relate. We believe that mentally ill people have the capacity to reintegrate into the larger society eventually, but they have to take the small step of learning how to integrate here first."

In practice, in the community residence, real-world responses to client behaviors get mixed in with therapeutic responses. The kind of reponse a client gets depends upon the mood of the client, the situation they are in, and may also depend on the patience level of the staff person involved. Sometimes staff will try both these methods to see which gets a positive reaction from the client and/or relieves the staff person's own tension. As one staff person said:

> "I always try just asking the client to do something they're supposed to do. If that doesn't work, I try something else. Like we have this client Joe - he won't take showers.   I don't know why. He gets in a mood and he won't take them, even though, when he finally does breakdown and take one, he comes out feeling all peppy.

I try joking with him: Boy Joe, you stink. Sometimes that
works. Other times I end up doing a contract with him. He
has to take so many showers a week if he wants to go to
dinner with us on Saturday. That usually works. But I
don't like doing contracts with people unless I have to."

1.2   The Residents

> "One of our residents, who was going to be moving into the house when it opened, came to the town meeting and stood up and spoke in favor of the house. A business man from town jumped up and yelled at the resident, "How would you like to live next door to one of those people?" The resident said, "I am one of those people. I live in the Highland community residence program." (House Manager, Group Home)

There is very little interaction between people in the community and residents. Trying to get interviews with residents was instructive in this regard. My request for interviews was screened by the staff, vendor administration, the human rights committee of each house, and belatedly, by the legal department at DMH. Through this process, it became apparent to me that residents live in the community under an ambiguous form of guardianship, and not as independent adults capable of interacting directly with outsiders.

In one of the group homes, staff requested that I leave the door open while interviewing one of their residents. This particular resident seemed extremely manipulative and perhaps staff were concerned that I might be conned into something. As it was, the first words out of the resident's mouth were, "Can you get me out of here?" When she found out I couldn't, she lost interest in the interview.

Staff in the group homes, in general, were cautiously

supportive of the idea of asking residents their opinion about their housing situations. Their caution seem to stem from a desire to protect the residents from anything I might say to upset them. Conversely, they seemed concerned that the residents may say something to upset me. They also seemed wary of me uncritically accepting any distortions in the resident's presentation of life in the residence. Ideologically, staff were, for the most part, committed to letting residents express their opinions, but practically, they had their doubts about the residents' ability to do so.

Screening group home residents' interactions with outsiders is a process that occurs, not always by design, but often as a result of residents engaging in community activities as a group. Residents grocery shop, go to movies, resturants and malls in a group. In a group, the resident's interaction with the community is usually directed by the residence staff. As a staff person noted:

> "Some of our clients are easily identifiable as mental health clients, others aren't. But put them in a group with two staff people directing the action and its obvious who they are."

This kind of interaction can only lead residents to feel more separate from the community, not a part of it.

While the need exists to protect residents and to minimize the chances for misunderstandings between the residents and the

community, the need also exists for residents to practice
dealing with the community directly, and for the community to
learn to understand and accept people with mental illness. My
interviews with residents suggest that they need more
opportunities to exercise their autonomy and express their
individuality. They need opportunities to get to know people
in the community, and for people in the community to get to
know them on a one to one basis. Prejudice and stereotypes
thrive in an atmosphere were people can be addressed as an
undifferentiated group.

How do residents feel about living in a large group?
Relatively few residents were willing to talk to me. Those who
did expressed mixed emotions, some very positive, some very
negative and sometimes both feelings in the course of the same
interview. Many clients seemed to feel positively toward
staff. As one resident said to me:

> "I like the staff. A lot of them have left to go on to
> school. Its funny, you just get used to them and they
> leave. Some of them stay with the agency though and you
> hear about them once in a while."

This resident highlights the problem of forming close
relationships with staff - "you just get used to them and they
leave." Because community residential work is so stressful,
and so underpaid, most staff tend to leave the job after a
year. Tenure of longer than two years is exceptional.

Despite her experience with frequent staff turnover, when I asked this resident if there is anything else she'd like to say before we end the interview, she responded enthusiastically:

> "I'd just like to say, the best thing about this house is that the staff are congenial, and try very hard to be helpful to people and do the best they can by us."

Another resident indirectly indicates that he feels positively toward staff:

> "What do I like about the place? Its a roof over my head, a hot meal. I'm not all alone. Sometimes I wonder if staff know what they are doing. If this was an alcoholic halfway house, they wouldn't put up with a lot of the crap they put up with here. We've had some real winners in this program: junkies, drunks, thieves. On a few occassions I've been physically threatened. I go to staff when that happens."

On the one hand, this resident wonders if staff know what they are doing. Yet when he is threatened, he feels that staff people can protect him.

Another resident tells me:

> "I like being at the house. The staff are real good. You're with people. I like it better than where I was before because you're with people. I feel better more of the time. I know the staff. It feels safe here."

What emerges from my interviews with residents is that residents feel safe with staff. The need for safety seems to be uppermost in most residents' minds. They speak of safety from other residents, safety from their own fears and feelings of lonliness and anxiety, feeling safe in that staff are seen

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as stable, dependable and in control. What residents seem to appreciate most in staff is their ability to create this sense of safety.

All the residents I spoke to said a group home was not their ideal living situation. With the exception of one resident, all the residents I interviewed had positive things to say about the house in which they were living. Yet, their approval was in most cases, not whole hearted. Residents seemed to resent, or in some cases were resigned to, having little choice in the matter of their living situation. A choice among the alternatives of staying on the ward, being discharged without any definite housing arrangement, or being discharged to one of the few openings in a group home, is really no choice at all.

Residents were well aware of the fact that living in a group home kept them off the streets and out of shelters and state hospitals. For that, they were grateful, sometimes begrudgingly so. All of them still hoped that they could regain more control over their own lives. Some residents saw the group home as a step toward regaining that control, others saw it as another stumbling block.

Another common area of resident dissatisfaction was the number of people in their group home. Most residents felt there were just too many other residents. Residents expressed impatience,

fear or even disdain of other residents and wished there were
fewer of them around. This seems paradoxical until you
consider that few people want to identify themselves as
mentally ill. The great stigma associated with mental illness
causes residents to want to distinguish themselves from those
other "crazy" people.

In addition to residents not wanting to identify with other
residents, many of the people I talked to cited the practical
inconveniences of living with a large group - lack of privacy,
constant compromising, less individual attention for
themselves. They also pointed out the difficulties of living
with other mentally ill people.

Even when the resident himself/herself is feeling stable,
he/she is often exposed to the added stress of riding out
another resident's emotional crisis. As the number of
residents increases, the likelihood someone may be in crisis in
any given week also increases. Living in a house where crises
occur on a regular basis surely makes it hard for residents to
live a normal life. Moreover, residents' feelings of
resentment at having to put up with these recurrent crises are
only exacerbated by the fact that they have no choice in
deciding who gets to live in their residence.

The difficulties involved in living with a large group of

people and the lack of choice about where and how they could live were issues brought up by most of the residents interviewed.

One resident I spoke to seemed cautious about expressing his views in the first half of the interview. His comments were fairly neutral:

> "I lived with four people in an apartment before I lived here. I liked living there. I prefered it to living here. Before that I was at the state hospital for four months.
>
> Yes, I like living here. It's comfortable. The furniture is new. The house is layed out nicely. Having the stores close by is helpful. People are always popping down to the stores.
>
> My ideal situation would be a small efficiency apartment. I'd like to get a job and start working. I'd like to save money. Now I'm in a day program."

As the interview progressed, he became more expressive:

> "What don't I like? Well, it could be smaller. Twelve people is too many. Four people was a good number. With twelve people we constantly bump into each other. Every time you turn a corner, you bump into someone. I think three or four people apartments are better with less staff around. I'd like to live independently. But I think twelve is too big for anyone - just too big, too many people.
>
> My social worker at the state hospital found the place for me in the apartment program. Yes, I could've turned the placement down, but there weren't any other places to go. I could take it or leave it. But who wants to stay in the state hospital?"

Another resident began the interview by telling me exactly what he thought of the house, in answer to my question about how

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long he had lived in the house.

"I've been here too long - seven years. It's not always
easy living with other people - conflicting personalities
and all that. Some people are so overly dependent. They
can't buy their own cigarettes. They can't take the bus.
Some of these people are so manipulative - they try to get
somebody else to do it for them. They are spoiled, lazy and
manipulative - used to getting their own way.

The other thing that bothers me is the place is often filthy
- feces on the toilet seat, dishes left lying around.
Nobody cleans up after themselves. That's institutional
behavior. It's like living in a nursing home or a prison.
Some people are just slobs."

When I asked this resident where he'd like to live instead, he

replied:

"I'd like to live in an agency owned apartment without a
roomate. You can have conflicting personalities with a
roomate. I want an apartment just for myself.

I used to live in an apartment with roomates. I started
getting scared and paranoid - all lonely and scared and
screwed up. One of my roomates started using me, pretending
like we were friends and then taking me for all he could.
He took my clock radio, my wallet. Then he started acting
cute, like he'd gotten ripped off too. Staff weren't around
that much. They couldn't figure it out.

Money is a limitation on where I can live. I would like my
own apartment with minimal supervision in a place where
there are just a few other agency apartments in the
building. Roomates can be tough. I wouldn't want someone
who just came out of the hospital living with me. It's
rough up there.

At the end of the interview, this person volunteered the

information that he was a reformed alcoholic. He went on to

explain the philosophy of Alcoholics Anonymous to me:

"I go to AA meetings. They tell you to stay away from old
friends you drank with, get rid of old friends. It's not a
place to go to make friends. You go there so you won't

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drink. That's the main purpose. It'll work for you if you want it to. You've got to want it to. Don't stay at home and feel sorry for yourself - keep busy. That's what they tell you. I have a sponsor in AA - someone I can talk to if I'm heading for trouble. It helps me to talk to him."

It occurred to me that this resident was using the AA philosophy in thinking about where and how he'd like to live. He wanted to "get rid of old friends", to be away from other residents with their "institutional behavior". He didn't want to live with anyone coming out of the hospital. Like old drinking buddies, they might draw him back into mentally ill behavior.

This resident was also very definite about wanting an apartment which was linked to the mental health agency. He would then have someone at the agency like his sponsor at AA, someone who understood his old life, someone whom he could call when "I'm heading for trouble."

The one thing this resident did not appear to carry over from the AA philosophy to his way of thinking about his mental illness, was the AA insistence that people accept the label for themselves of "alcoholics". AA members take pride in the fact that they have the moral strength to publicly acknowlege that they have a problem. AA members are encouraged by the group not to be ashamed of their past but to learn from it, so that the past does not keep repeating itself.

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This resident did not see his membership in the group home in that same kind of positive light. Nor was he encouraged by the group to do so. That kind of radical thinking about mental illness as a positive source of identity, is just begining to emerge in some group homes. Interestingly, the therapist I spoke to at the private residence drew parallels between her group home and AA:

> "The support networks formed in group homes are essential for mentally ill patients. Like alcoholics who go to AA to be with other people who understand what it´s like to be addicted and are trying to give it up, mentally ill people need to be around other mentally ill people who understand what it is like to have this illness. Group support is crucial to change."

Clearly, it is even harder for people in publicly funded residences to see their inclusion in a group of mentally ill people as a source of positive self-identification. These residents are doubly stigmatized by being both mentally ill and indigent.

Another resident I spoke to was glad to talk about things she liked about the residence, but was hesitant to talk about things she didn´t like. It seemed as if she felt the way the mental health system worked couldn´t be changed, and she was resigned to making the best of things as they were:

> "It took a while to adjust to living with ten people. Of course we´ve all got our own bedrooms here. I like that better. At the other residence, they have to share a bedroom. I don´t like that idea. Of course, I´m the oldest here, but I get along pretty good. Sometimes we sit around and talk and have a good time. Sometimes I just stay out of

the younger peoples way. I have my friends at the drop-in
center. Sometimes they come over.

We have a certain amount of freedom here. We can be out
until eleven weekdays and twelve o'clock on weekends. None
of the women go out much though.

I used to live with my sister and her son, but she was
alcoholic and it didn't work out. My social worker filled
out the application for me to get into an apartment. I had
to wait three months and be interviewed two or three times,
but then I got into the apartment, but then it didn't work
out. I couldn't stand my roomate screaming and hollering at
me all the time. She used to yell and scream at everybody
but I couldn't stand it. Now she lives by herself. They
moved her to her own apartment because she was always
yelling at somebody.

I like living with people of all ages. Where would I want
to live ideally? Oh gee, I don't know if I can say it.
O.k. I'd like to live in an agency apartment of my own,
maybe a one bedroom or a studio. I would like to have two
or three rooms in a regular apartment house.

What would I change here? I'd change talking to the staff
so much sometimes. Sometimes they coax you to talk and you
just want to be alone. You know what I mean?"

Like these residents, all the other residents I interviewed had

lived either with family or with roommates in an apartment

supervised by a mental health agency. In the case of the

resident quoted above, and the resident quoted before her,

tensions between the roommates made the living situation

untenable for them. In the case of the first resident quoted

in this section, the program director decided to close down the

supervised apartment in which he was living because "people

were not getting along with one another".

When I interviewed residents, I only inquired about their most

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recent housing history, because most residents seemed reluctant to delve too deeply into their past. Several residents' accounts of where they had lived prior to entering the group home, ended abruptly when they came to the time in their lives they had spent in the state hospital. They seemed acutely aware of the negative connotations of having been a state mental hospital patient. They also seemed fearful of evoking any of their painful memories of the time they had spent there.

Moreover, most of the residents I spoke to were over thirty. Any lengthy account of where they had been and why they moved on would have required them to reflect on why they had no permanent ties to someplace or someone, at a time in their lives when most of their peers were firmly settled into a pattern of relationships and mutual obligations.(15) Such reflection undoubtedly would have been painful, particularly in the presence of an interviewer.

One of the young residents I spoke to voluntarily recounted to me all the places she had lived, taking care to get the sequence and the amount of time spent in each place correct. She seemed to take the instability in her past as a given. She also seemed to try to remain indifferent to her surroundings, as though where she would end up in the future was beyond her control as well:

> "I'm twenty years old. I left home at sixteen. When my
> parents were divorced, first I lived with my mom, then my

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dad. Then I left and lived with friends for a while. Then
I was on the Lydia McCormack unit at H.(a private
psychiatric hospital) for six months. After that I was at
the Institute for Living Skills (another private psychiatric
hospital) for a year and a half. Then I went back to live
with my mom but she couldn´t handle me. So I lived with my
dad for three months. Then I ended up in the state hospital
for a while. From there I went to March House (a group
home), then to a supervised apartment, and then I had to go
back to H. for two months. After that I came here and I´ve
been here for four months.

This resident is describing the early stages of a life pattern

common among people with severe mental illness. They bounce

from relatives to inpatient units to community residences and

back again. Each new move contributes to their growing fear

and despair that they will be unable to make it anywhere. The

young resident quoted above has learned to be indifferent to

her surroundings, to feel that she has little control over what

they are like or how long she stays in any one place. Like the

older woman resident quoted earlier who said, "I don´t even

know if I can say it", when asked where she wanted to live,

this young woman has learned to try not to care too much about

what happens to her.

Still this resident appears hopeful about her present

residence:

"I like the structure they give you in this house. I need
it in order to deal with the problems I have. They were
real lenient in the last group home I was in and I don´t
think I did as well.

My first visit to this house scared me but I didn´t have
much choice. I don´t know how long I´ll be here. I want to
move into Morgan house (another group home run by the same

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agency).   They have more independence there.

I don't dislike the rules and regulations so much because I understand they're for our own good, but they could be a little more understanding with people here, a little more sensitive to peoples' feelings.

I kind of have a problem being oversensitive myself, I guess, anyway. But I think it's better to talk to you sometimes if you're having a problem instead of always telling you to follow the rules.

Eventually, I want my own apartment. This time I want to be alone. I don't like a large crowd of people around me. I'd like a studio apartment in a regular large building."

Of the nine residents interviewed for this thesis, two said

they wanted to return to their families after living in the

group home. These two were among the youngest of the residents

interviewed. One resident said she did not want to think about

living anywhere else. She liked it at the house in which she

lived. This particular resident was fearful of losing her

place in the residence at the time I interviewed her. Because

she had been rehospitalized for several lengthy periods during

the past year, she was on the verge of losing her place in the

house if she was rehospitalized one more time, despite the fact

that she had been living in the house for four years.

The six other residents interviewed all said they would,

ideally, like to live in their own apartments. Five of these

six said they would like to live alone. The one resident who

did not want to live alone expressed himself very clearly on

the subject:

"You live by yourself, you get scared. I had an apartment
by myself but there was nobody to go out to dinner with,
nobody to go to the dogtrack with or to the baseball game.
I wouldn't want to live on my own again unless I had a
friend, a boyfriend or a girlfriend - then it would be o.k."

The other five residents who wanted apartments to themselves
seemed primarily concerned, not with companionship, but with
privacy. Their comments support the therapist's view that they
need the "boundaries of the four walls to feel like people are
not intruding" on them. Moreover, several residents emphasized
the need for a small, manageable space like a studio. A few
residents pointedly remarked that they would like to live in a
"regular" building: a building in which they are integrated
with other apartment dwellers, a building in which they don't
have to be reminded of their status everytime they walk through
the door.

Three of the five residents who wanted to live alone also
expressed great interest in maintaining their ties to the
mental health agency that ran their group home. They viewed
the agency as a source of support and friendship, and even as a
kind of insurance policy. If they tried and failed in
apartment living, they would only fall as far back as another
agency program. Their life would not revert totally to the
emotional turmoil they had known in the state hospital, or to
the despair they had experienced when living with relatives and
not recieving any mental health services. Continuing their tie

to the mental health agency made the move to an apartment a much less risky venture for residents.

The comments of the following resident illustrate just how risky a move toward more independent living can be for people who have lost years of their lives battling with mental illness. The hope that this time they might finally make it, balanced against the fear that their lives will come apart again, leads many residents to experience an almost unbearable level of tension and anxiety.

The resident describes her situation:

" When I was living with my father, I kept getting sick all the time. We lived in a trailor on a horse farm out in the country. I couldn't go anywhere because I didn't have a car and it was close quarters living in the trailor. I was very lonely. I had no friends, no outside acquaintances, no one to talk to.

It's funny you should ask me about my ideal living situation because I just found out I'm going to go there. I'm on the top of the waiting list for 75 Juniper Street. It's a big apartment building 4 blocks from this house. The agency helps us get subsidized apartments there so we only have to pay 25% of our income. But I have to wait for a vacancy. I have no idea how long it could be - 4 months?, a year? - no idea.

But I'm so happy I'm going there. I'm going to have my own one bedroom apartment. I know three people who live there. I've seen their apartments and it's really nice. The apartment building is right across the street from the bus stop. I can take the bus to my volunteer job downtown. I'm so happy about moving into the apartment.

I might have to adjust to being alone. It'll be hard going from a house with ten people to just myself. But I anticipate joining the cooperative. If you are in the co-op, staff from the agency meet with you at least twice a month. They have rules and a day program. They help you

get settled and used to the place - just like friends."

This woman went on to reiterate several times during the interview how much she looked foward to moving into an apartment. She gave me directions to the apartment building so I could see for myself what a nice place it was. She was ebullient and cordial all during the interview, her enthusiasm waning only when I asked her to describe things she didn't like about living in the group home.

I left the house and got into my car, quite certain that this woman would be successful in her new apartment. She was friendly, attractive and had a positive outlook on life. At the end of the driveway, I remembered to turn left instead of right so that I could see the apartment building into which she was moving. It was a fairly new, nondescript brick building which blended neatly into a corner of a downtown intersection.

I turned my car around and came back past the house to continue on my way home. As I was coming up to the house, the woman resident I had spoken to was walking down the sidewalk away from it. I was about to honk and smile and wave when I noticed she had her head down and her eyes firmly on the ground. The expression on her face was sad, almost stricken. The engaging young woman I had spoken to a few moments ago had simply disappeared. I realized how hard it is for residents, even

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residents for whom things were starting to go well again as
they were for this woman, to overcome the self-doubt brought on
by years of mental illness.

I think its fair to say that most of the residents who were
willing to speak to me did so because they had positive things
to say about the house where they were living. A few residents
seemed to be motivated by having negative ideas about their
group home which they wanted to express. Yet, when given the
opportunity to express them, they seemed constrained, as if
they felt that the information might be used against them.
Similarly, many of the residents who came to talk approvingly
about their group home, seemed uncomfortable when asked, "What
don´t you like about living here?"

This sense of restraint in saying negative things on the record
is a rational response to a mental health system that tends to
take negative opinions of its services as evidence of the
client´s deficiencies. Staff are aware that clients often
have justified complaints, valid opinions and insightful
observations about how the residence program is operated. Yet
staff themselves often feel unable to influence how the program
is run or to make their opinions heard. If staff feel unable
to make their opinions count, consider how much less able to
influence their environment residents are likely to feel.

Residents negative comments tend to focus on other residents.

Given residents´ feelings of a lack of control over who they

live with and how they live, this is not surprising. In

addition, it is easy to see that living with other people who

engage in bizarre, egocentric, or highly emotional behavior on

a regular basis is disturbing for anyone. It is no less

disturbing for mentally ill residents just because they are

also disabled. They may even have less tolerance for such

behavior.

Residents seem to prefer identifying with and interacting with

staff. The following quotes from residents illustrate this:

> "I get along well with other residents. When I don´t, I can
> go to the office and talk with staff about it. I just don´t
> pay attention to other residents when they start acting
> crazy. They´re sick people that´s all. It´s not the
> staff´s fault if they act like that. New people come into
> the house but some don´t stay here. Some have to go back to
> the hospital. No, it doesn´t disrupt my life."

Another resident said:

> It would be nice if we had fewer people here. It would be
> ideal with six people. Then the staff could do more
> activities with us. We don´t get out enough. The regular
> staff is gone on weekends and the relief staff don´t take us
> anywhere. I just want to get out and do something - go to
> picnics, the movies, malls, have parties, just go shopping.
> I don´t like to sit in the house all weekend."

Another resident commented:

> "I like it here. There isn´t any other housing I´d rather
> be in. I don´t like it when people really get sick and yell
> and scream."

1.3   The Disability

> "It's a scary job sometimes, but not in the way most people
> think. People are misinformed about the mentally ill. They
> think - oh a mentally ill person - they might stab me in the
> back while I'm sleeping. With most of the mentally ill,
> they're usually only aiming at themselves." (Staff person)

Staff, administrators and some of the Area Office personnel
that I talked to, had strong opinions about what it means for a
person to have mental illness. Their comments focused not on
symptoms or diagnoses, but on the trouble mentally ill people
have trying to live day to day. Like the staff member quoted
above, many of the people I spoke to said that mental illness
is characterized by low self-esteem and despair.

Mentally ill people are often aware that they don't fit into
society, and that they have little control over their own
lives. There is little social acceptance or understanding of
their illness, and few attempts to accomodate their disability
within the normal social environment. There is no mental
health equivalent of curb cuts and handicapped parking for the
physically handicapped people, or Special Olympics and special
needs education in public schools for the mentally retarded
people.

The disability of mental illness is widely misunderstood and
negatively percieved. Popular culture tends to reinforce

negative images of mentally ill people by portraying them as

psychotic killers or contentedly deluded bag ladies. These

images perpetuate the myth that mentally ill people don't

experience normal feelings of pain, happiness, desire and

regret.

As a social worker who works with long-term mentally ill said

at a conference on services for mentally ill people, "Sometimes

I think I contribute to the negative images people have of

mentally ill people. I never come home and tell my kids or my

friends about the nice normal things my clients did during the

week. I come home and tell them about the one bizarre thing

that one client out of thirty did during the week, because it

makes for a much more exciting story. It makes my job seem

more exciting."

Many staff people interviewed commented on the struggle

mentally ill people have in developing a positive self image,

and how prevalent despair is among their clients. The

following comments illustrate this:

> "All the clients here have a pretty good reason to want to
> kill themselves. The nature of their illness is so
> debilitating and so frustrating to them. They've often been
> victimized. They've lost so much time in their lives going
> up and down with the illness that they never had a chance at
> many of the achievements the rest of us build our self
> esteem around: a happy marriage, a stable job, home,
> friends.

> Many of them are in their forties or older. Even the
> medication they take to stabilize themselves has such awful
> side effects. It's an ongoing nightmare that they live and

I think most of them wonder if they'll ever be able to reclaim their lives. Still, I think most of them manage to have some kind of optimism that they can still make a good life for themselves."

A staff person at another residence said:

"Everyone here has been suicidal at some point in their lives. When they're delusional or paranoid or depressed, it's hard for them to communicate what they are going through and they get locked in with their own despair. Holidays are usually the worst times for our clients.

As the staff person pointed out earlier, mentally ill people don't have many of the sources of self-esteem that most people do: family, friends, work. A parent of a mentally ill person also points this out:

"Mentally ill people feel incapable. They've lost confidence in their ability to do things for themselves. They see their friends getting on with their lives. Meanwhile they don't have any money, any job, and the longer it goes that way, the more incapable they feel."

In the course of their day in the work shop, or the day program or in the residence, clients may have few opportunites to build their self esteem. Work shop programs are often limited to repetitive tasks at low pay. This kind of work for mentally ill people is often justified on the basis of the client's spotty performance, poor attendance and inability to pay attention to the work. Clients may get payed wages as low as one dollar an hour.

Mentally ill persons who are enrolled in day programs spend the time in various therapy, recreational or living skill groups with frequent breaks for cigarettes and coffee in between. This kind of structure is based on keeping the program low pressure, but it can also make it boring for clients as well.

In the residence the clients are subject to more structured activities. They go to group meetings, do required chores, and go on group outings. Clearly, in the residence as well, the opportunities to show initiative, to be expressive, or to feel a sense of personal accomplishment, are limited.

Staff members, in general, feel that the residents need this much structured activity in order to get anything done. Left to their own devices, staff and administrators contend, residents would not do anything for themselves. As one administrator put it:

> "Regardless of diagnoses, these clients have functional deficits. That's the one constant factor across clients. They are unable to maintain a job, an apartment or self care. Healthy people have the ability to impose structure and routine on themselves. They are able to manage their time and their energy because they are able to plan ahead.
>
> Mentally ill people can't do this because of several reasons: a) the nature of their illness, b) they never learned how, or c) it's too stressful to self manage.
>
> I jokingly call some of our residences `little military schools´. They are very scheduled, very structured. Each resident has a case manager to help them manage their affairs. Many residents are able to internalize that structure and advance. I've seen one client do the whole continuum from lowest functioning to aftercare, but I've seen many move up a level, or function better within the

level that they entered. It's fair to say that clients come in very dependent and gradually assume more self management."

Another staff person described to me exactly what she meant by structure:

> "By structure I mean we tell them how to get from point A to point B. Every Tuesday night we do menu planning and grocery lists. On Wednesday we do grocery shopping. Thursday its group meeting and psychiatrists visits. Friday its group recreation. Saturday is banking day and on Sunday are activities that the clients suggest. Every week is the same.
>
> This is a very highly intelligent group of people here, but they need the structure to get things done. They are really independent as far as entertaining themselves though. I always half-jokingly say that the worst things in the world for mentally ill people are t.v., computers and religion. But this group makes pretty good use of the t.v. They watch McNeil/Lehrer and Jeopardy every night. They play Scrabble. They are unusually independent as far as entertaining themselves goes."

This staff person's quote is interesting, not only for what it says about the need for structure, but also for what it says about the conditions under which clients use unstructured time productively. Not surprisingly, residents don't need to be "structured" into doing things that they find enjoyable. A SRO administrator that I talked to suggested that incentives could be used in many instances in place of structured activities.

> "There are other ways to keep clients from being isolated and withdrawn besides forcing them to cook and do chores. Mentally ill people's problem is psychiatric not rehabilitative. For most of them, they don't need to relearn how to cook and do the wash. They know how to do it and they just don't want to. If a staff person says `hey, let's talk while you do your wash.´, they may think its worth their while."

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Another staff person, however, points out the difficulty of

using an incentive-based approach in a group setting:

> "We don't care how they decide to do the chores, just that
> the chores get done. These clients have a hard time problem
> solving. They feel they're adults and they don't need
> rules. But none of them take on responsibility voluntarily.
> They always think, well if I don't clean up someone else
> will, or it'll get done. They don't stop and think well who
> is that someone else?
>
> If there were no consequences for not doing things, they
> just wouldn't do anything. Like the out of the house from 9
> to 3 rule - clients are adamant about how much they don't
> like that rule. But they wouldn't leave the house all day
> if we didn't have it. It's much harder to set rules with
> them because they're intelligent enough to know how things
> should be done without the rules. But that doesn't mean
> they'll do it."

When this staff person comments about how residents don't "take

on responsibility voluntarily", she is talking about

responsibility to the group. Because residents are sharing a

space with other residents, they have an implicit

responsibility to help maintain that space. The fact that

residents don't recognize their responsibility to the group

doesn't necessarily indicate a lack of problem solving ability.

More likely, it indicates an unwillingness to be part of the

group. The Following comments by the SRO administrator support

this view:

> "We do provide structure but its not forced. We have a cook
> who calls everyone to dinner at the same time every night.
> Staff schedules are pretty stable so residents know their
> favorite staff person will be there on a certain day.
>
> The kind of people we get aren't interested in interacting
> with a group. We try to do things on a one to one basis.
> Not everyone needs to learn how to do laundry.

The problem for our clients is not a lack of skills, not a functional deficit but an emotional disability. Their emotions have gotten stuck in an early stage of development and they go around in circles trying to deal with feelings you and I take in stride.

They need TLC on a one to one basis to help them break out. When they feel good about themselves, they can do their laundry, cook dinner, wash their hair, whatever. When they feel bad, all the prodding and behavioral cueing in the world is not going to get them to do something."

This administrators's comments suggest that a potent source of client self esteem and motivation is their relationship to a staff person, that "TLC" can help make the difference for a client between feeling good and thus motivated to do things for themselves, or feeling bad and disinterested in self-care. She goes on to say that TLC is not the product of group interaction but of individual relationships between staff and residents:

"We try to build up relationships between an individual staff person and a client. Clients are interested for the most part in interacting with other clients, or in talking to staff as a group. They want the staff person's total attention for them. That's really their biggest incentive to come out of their rooms."

This administrator also suggests that the structure of a group home, far from relieving the pressure on residents by removing the need for them to make decisons by telling them, "how to get from point A to point B", actually increases the demands made on residents:

"There's a large population of mentally ill who don't fit into a group home situation. Psychiatrically they are too fragile and behaviorally they function poorly.

Group homes are like summer camp for adults. It's like,

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o.k. campers, now we all eat our breakfast. Now lets all do
our laundry and go to our activity. Time to make our beds
and clean our rooms. You have to be pretty adaptable and
pretty compliant just to handle that.

Most psychiatric clients can't. Their nerves are raw. What
they need is a lot less stimulation and a lot fewer demands,
not more. If you keep at them to wash their face and make
their bed, they just might sock someone. They need to take
things in more slowly and do things on their own terms.
Group homes are a babyish way to treat adults."

1.4 Group Process

"Lots of clients say they don't like living here because of the stigma, noise, dirt, number of people. It's hard to tell if those are the real reasons or if they are just being negative.

Socially its hard to live here. Everyone knows each others business, talks about each others business. There's always someone going through a hard time and that destabilizes everybody.

On the other hand, I think that living alone, or having more independence like in an SRO would just change the problems. There would be more acting out instead of talking out painful feelings as we do here. I think clients would feel less safe without staff around. I think it would just be different forms of discomfort in those other living situations." (Staff Person)

This staff person in trying to evaluate the relative advantages and disadvantages of group home living, as compared to clients living in and SRO or an apartment, touches on several issues crucial to understanding how, and for whom, group home life is beneficial.

The first issue has to do with resident choice. Are residents capable of deciding for themselves where they should live? Would their decision be based on "real reasons", or would it be based on the disordered or destructive thought patterns that characterize long-term mental illness?

The second issue this quote raises is the forced intimacy of group home living, not only in having to be involved in other

peoples problems, but also in having to talk about your own.

The third issue is the group home's capacity to provide a sense
of safety and stability because of the constant presence of
staff, and their involvement with the residents over time.

Finally, the fourth issue the staff person quoted above touches
on are the inevitable trade-offs involved in any living
situation. What level of adjustment and satisfaction should we
expect from long-term mentally ill residents living in any kind
of community residence?

Several staff people interviewed commented on the issue of
residents having a choice about where they live. For the most
part, staff felt that residents wouldn't exercise that choice
in their own self interest. At the same time, they recognized
that residents had to give at least minimal consent to group
home living in order to benefit from it.

> "Some clients here wish they were in a staffed apartment
> instead of a group home. There's a few clients who want to
> live totally alone. The rest know that they can't make it
> in those situations, so they make the best of it here.
>
> There are some guys here now who used to live in a
> supervised apartment. They had a lot more freedom there.
> They had their own keys, they could come and go as they
> pleased. They came here and lost that freedom.
>
> Here we might have eight people watching television in a
> room at one time and staff are always checking up on people.
> Stuff like that really bothers some of these guys.
>
> The one guy who is most outspoken about how he'd rather be
> in a supervised apartment really couldn't make it in one.

He's here because he has to be. He wouldn't feel safe
without the supervision.

His always wishing he was back in a supervised apartment
gets in the way of him getting what he could out of this
program. Instead he always complains that there are too
many people and too many rules and staff are trying to run
his life."

Another staff person told a story which shows how clients who

don't want to be in the group home can seriously disrupt group

home life, and how the lack of alternative placements can make

the client's supposedly voluntary placement in a group home

seem more like an involuntary one.

"We had a client start here six months ago when we opened
this house. She had been in another one of our residences
for three years prior to that.

Clients have to have some degree of investment in the
program and she never did. She would sit in her room and
smoke which is against the rules. She was actively
psychotic.

She kept asking to go back to the state hospital and we
couldn't send her because she wasn't violent. She would do
things like go out on the front lawn and lay down and pull
her dress up over her head. Finally, she assaulted our
house manager and then she was able to go back to the state
hospital.

It was obvious to all of us, staff and residents, that the
client didn't belong here. She said, "I just want to sit
and smoke cigarettes." But there was nothing we could do
about it."

A staff person gives another example of a resident who didn't

want to be in the group home and eventually got her wish:

"Betty is the first client I've seen move into an apartment
in the one and a half years I've worked here. But I don't
see it as a graduation. I see it as an escape. She
couldn't deal with the crowd anymore and finally they let

her have an apartment. I don't feel like she's ready to make it on her own in an apartment."

A therapist from a private residence added her own story about client resistance to group home life:

> "For example, I have a patient who is a schizophrenic woman. She is living by herself in an apartment now. I've known her for six years and I knew her when she was living in a group home. She didn't like living in the group home, but it was there that she learned some of the skills that enable her to cope now.
>
> She still lives a fairly socially isolated existence, but not as bad as she would have been without the group home experience. She likes living alone, she needs to live alone, she needs the boundaries of the walls to feel people are not intruding on her."

Whether its resentment over the "loss of freedom", or wanting to do nothing but "sit and smoke", or having to "get away from the crowd" to feel that "people are not intruding", its clear that there are many long-term mentally ill people who cannot, or will not invest in group home life. It is also equally clear that without that investment, group home life is frustrating to the client, and to other staff and residents as well.

Surprisingly, the issue of forced intimacy or having to become involved with other residents, was seen by staff and administrators as more of a problem in small groups than in large. Some of the staff and administrators I spoke to said that the size of the group and the amount of staff supervision

were major determinants of the level of intensity of
interaction in the house. The concensus was that smaller
groups and less staff supervision generally led to more
intense, more intimate living situations. The therapist quoted
above went on to say:

> "Smaller groups are stormier than larger ones. They can
> also be more cohesive and more supportive. They are more
> intensely personal. That´s why we settled on the number
> four for a supervised apartment - two is too intimate, with
> three somebody always gets left out, so four is about right.
>
> In large groups, the danger is just the opposite - someone
> ending up in the woodwork and not getting enough attention.
> In large groups, though, residents tend to unite around
> dealing with everyday life in the residence."

A staff person at another residence lends support to the

therapist´s view:

> "Group milieu is hard to build in a four person apartment.
> It´s more work for the clients just to get the chores done.
> If one of the four is in crisis, it has a much stronger
> impact on the other three. Also there is more splitting
> into factions: one against three, two against two. There´s
> also more of a tendency for residents not to invest in the
> group to begin with, to try and act as if they were living
> alone.
>
> Larger groups tend to diffuse the tension. People can
> withdraw without being missed, then rejoin the group when
> they are ready. There´s more people to take up the slack.
> We tell residents that everyone has to feel responsible to
> the group. You can´t just think of yourself. Another thing
> is that residents find it easier to confront each other in a
> group. I think that for the four person apartments to work,
> people have to be really high functioning. They have to be
> able to pull each other through because there aren´t staff
> around to do it."

Later in the interview, this staff person added:

"Whenever you have twelve people living together you're
going to have tiffs and spats and some people who downright
hate each other. We have two women here who couldn't even
talk to each other when they lived in the four person
apartment. Now they ocassionally sit and have coffee
together and talk to each other."

Another staff person in the same residence brought up the issue

of small versus large group dynamics in the process of

describing to me how the residence got started:

"I used to work at the duplex we had on Maple St. It
started out with four men and four women on each side. We
tried to break it down more, to make it more like a big
house of eight. We had a woman client move in on the men's
side and we didn't want her to feel isolated over there so
we wanted to bring the two sides together.

We felt it would be better for the clients if both sides
socialized together more. With just four clients you end up
with one being left alone a lot. Say, for example, if two
clients go home for the weekend, and the third stays in his
room all day, the other sits in front of the t.v. all day by
himself.

People also got into more intense interactions when there
was just four in a group. We had this one client, Helen,
who liked to have the t.v. all to herself. A lot of clients
felt intimidated by her. She'd be watching t.v. in the
living room and another client would come in and she'd just
look at him, just turn and give him this look and he'd take
off. That couldn't happen with twelve people. People just
wouldn't let her dominate the living room like that.

It's hard to tell if Helen intimidated people delibrately.
I mean it was delibrate in that she liked having her space.
But it wasn't delibrate in that if she looked at somebody
and they stayed in the living room anyway, she wouldn't say
anything to them or ask them to leave or anything. She
might ask them not to change the channel, which she sorta
had the power to do since it was her t.v."

Group process was seen by many staff as a way of diminishing or

diffusing intense interactions between residents, or between

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residents and staff. When I asked the staff member quoted
above how she dealt with residents who intimidate others, she
said:

> "We always have two or three dominant clients in a group who
> give their input on everything. These clients sometimes
> make it harder for others to be assertive. We try to
> counteract some people's tendency to dominate with group
> meetings. In group meetings we encourage the quieter ones
> to speak up, and we point out if a dominantor is taking over
> the conversation."

Ironically, the group meeting, the very mechanism for diffusing
the tensions in individual interactions, often serves to
concentrate those tensions into one intense weekly airing of
feeling. A staff member at another residence gives an example
of this:

> "On Thursday we have three people on till eleven because we
> have community meeting and a lot of stuff comes up.
> Sometimes someone gets really focused on and its really
> uncomfortable. Sometimes residents' anger focuses on staff.
> At one meeting, I really got blasted by a resident that I
> had set limits on the previous week. I'd seen her and
> talked to her several different times after setting the
> limits and she wasn't upset. I think it wasn't until
> community meeting that she felt able to let out her anger."

Group meetings served other functions in addition to being an
outlet for interpersonal tension. The staff person quoted
above pointed out some of the other purposes of group meetings:

> "Community meeting can be very intense. Sometimes when
> someone is really getting focused on, I try to widen it out
> by bringing other staff or residents in on it. The meeting
> can be a source of support, a place to deal with tensions in
> the house.
>
> It's also a chance for residents to make decisions. For

example, they decided when the music room should be available for smoking, and when it can be used by someone who just wants to listen to music without someone smoking around them. The residents decided when somebody can substitute for somebody else on chores.

Residents will bring each other back to the issue when they are trying to make a decision - like saying - `Purple people has nothing to do with smoking in the music room. Stop talking about purple people, and tell us when you think we should allow smoking in the music room.´

Sure they deal with heavier stuff too. Recently a resident returned to the house after being hospitalized. The other residents were angry that she was back because she was verbally abusive to them and angry with them all the time. They were able to express this at community meeting. I think residents would protest wildly if we ever canceled community meeting."

A staff person in another residence also described the group meeting as having many functions. Her comments also indicate that she sees the group meeting as an indispensable emotional outlet for residents:

"Community meeting is once a week with a rotating chair. The chair asks each client what they want on the agenda. Most clients have to learn how to give just the topic and save their feelings about it until its time for discussion.

Sometimes the meetings are very task-oriented. Other times we get into interpersonal issues and staff issues. Its not supposed to be group therapy but sometimes it works out that way.

It can get very intense with people expressing a lot of anger, a lot of sadness or happiness. We have to validate the feelings and help the clients deal with them. The intensity doesn´t make them feel unsafe as long as the staff maintain control of the meeting"

An SRO administrator that I spoke to contends that residents

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should have the option of choosing not to participate in group
activities like the community meetings. She felt that if
community meetings were really useful to residents,
participation would not have to be mandatory. She added:

> I think its true that a group can diffuse the interpersonal
> tensions you get with just a few people living together.
> But we have that advantage of a group in an SRO - even more
> so than a group home because we don't force people to
> participate. Residents here can adopt however much of the
> program feels comfortable to them. We work hard to
> establish relationships with them on their own terms.

A program manager in a group home, however, said that some
clients are frightened of the idea of being alone with
themselves and of having to make decisions. They want the
security of knowing that staff are around and in charge. She
said that living in a large group provides these clients with
the best of both worlds: the opportunity to withdraw when they
need to, yet the security of not being alone:

> "Living with three or four roomates in an apartment can be
> more intimate and threatening than a larger group where
> residents can withdraw from contact when they need to.

> I would say many of our clients can't live alone. They need
> the support of having people around to ground them, to help
> them structure their time, to give them the security of
> knowing someone will be there when they are in crisis.

> For example, we have a person living here who is psychotic
> every day. She has dreams at night that are terrifying and
> very real to her. She is frequently suicidal. Staff know
> to check on her at least once every two hours."

There is no fundamental disagreement between the SRO
administrator and the group home program manager. Rather they

are talking about different kinds of long-term mentally ill

clients. Clients who need more personal space versus clients

who are frightened of being alone. The difference between the

two types of clients is not one of functional level but one of

personal preference.

The following quotes illustrate the confusion that arises from

linking functional level to community residence type. One Area

Office official states:

> "The SRO is really appropriate for people who have more
> defcits in community living not less. People in a group
> home are more able to interact. It is discouraging for me
> to go to meetings where they propose one model for the
> world."

Another Area Office official said:

> "Group home settings work for people who are frequently
> rehospitalized, the really chronic cases. The people who
> are left in the hospital now are really sick. They need a
> lot of supervision and structure. You have to look at
> people's histories to decide where they will do best."

Just from my small sample of four group homes, it was obvious

that group homes could work for higher functioning, lower

functioning and mixed groups of clients, as long as there was a

match between client abilities and expectations and program

design. The two group homes that seemed to work the best in

terms of client satisfaction were at opposite ends of the

spectrum: one highly structured program with an explicit and

fairly inflexible set of rules and expectations, the other a

more loosely run, democraticly run program.

In the highly structured program there was a large percentage of women and dual diagnosed MH/MR residents. In the loosely structured program, most of the clients were young males with fairly short psychiatric histories. Clients in the highly structured program talked about needing the structure, and one said, "We live the life of Riley here." In the loosely structured program a staff person commented, "Clients feel positively about the house. They feel house pride. This is people's home. They have a say in how things are run."

The conclusion to be drawn from this is not that women or MH/MR clients always belong in highly structured programs, or that all young males with short psychiatric histories benefit from loosely structured programs. The point is to avoid being categorical. Both Area Office officials quoted above start from different premises to arrive at the same conclusion: that you can't use "one model for the world" and that "you have to look at people's histories to decide where they'll do best."

In contrast to the two group homes that were functioning fairly smoothly, the two other group homes in this study seemed to be experiencing more turmoil. In one group home this turmoil seemed to result from the extreme diversity of residents, such that there was no common denominator around which to build group identity. This diversity was unmanagable in a group because of the intensity of many of the residents' needs.

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Staff were pulled in many different directions at once trying to meet the needs of one resident, without slighting the needs of another.

In the other group home there was an obvious mismatch between client expectations and program design. The residents, primarily men age thirty through fifty, chafed under the structure the program provided. Many of them had come from supervised apartment programs and other less structured settings and they resented the new imposition of rules and regulations. They had built up a kind of negative group identity in the group home in which they saw life in the residence as them against us affair, staff versus residents.

All the staff at this group home commented in their interviews about the constant struggle with residents over the legitamacy of the program structure. The following comments by one of the staff illustrate the problem:

> "The whole idea of a group home is to invoke group process to help people get better. It's hard to juggle all the different client needs even in a relatively well matched group.
>
> But now we have a client who is borderline retarded. Emotionally, he acts about 8 to 10 years old. We have to do a lot more limit setting with this client, use a lot more behavioral techniques to get him to do anything.
>
> The rest of the clients here are capable of reponding to verbal requests and much more capable of acting independently. The majority of clients here, their problems are emotional - they get suicidal, paranoid or delusional.
>
> This client who's borderline MR has none of those problems.

He´s never suicidal or depressed. He just has a lot
oftrouble with daily living skills.

Yet when other clients see us saying to the MR client you
must do this, in this way, at this time, they think we´re
picking on him. They identify with him as a client more
than they identify with staff. It becomes an us against
them situation."

The success of any group home ultimately depends on building a

positive, managable group identity and clearly communicating

that identity to prospective residents and to mental health

personnel responsible for referring clients to residential

services. All group homes are not the same. Clients may do

well in one group home but not another. Some clients cannot

function in any kind of group setting. There is no formula for

determining which clients belong in which types of community

residences short of knowing both the client and the community

residence program well.

Moreover, even when a group home is designed for a particular

type of client, the overall client mix needs to be examined so

as not to overwhelm the program. As the following staff

person´s comments indicate, not only the individual client-

program fit should be considered, but also the overall level of

demand being placed on program resources:

"Some residents are much rougher to deal with than others.
We had one resident with a borderline personality disorder.
She was very clever at making people feel bad. She would
scream and yell at the other residents, or manipulate them.
Or she would try to pit one staff person against another by
telling each of them separately lies about what the other
had said.

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Its really uncomfortable to be around someone like that and watch her create problems you'll have to solve. But I view it as as a challenge to see how I can make the residence work.

You wouldn't want, couldn't handle five people like that in a residence. Staff would be crawling out at the end of the day on their knees. Nor could you have five actively psychotic people in a residence like this. People like that use up too much of the staff resources and if you have more than one or two in a group, other residents will be neglected.

I think it is better to mix functional levels though. The healthier residents often act as role models and care givers. Not only does that help lower functioning residents, the higher functionin people take pride in having something to give. The disadvantage of mixing functional levels is that lower functioning people slow the whole group down."

In summary, client fit with a residential program should be considered along a number of dimensions, not just functional level. The clients preferences, personality, psychiatric and functional history, and the intensityof his/her service needs all must be considered. In turn, the group home's program "identity" should be clearly communicated to the prospective resident and to their service coordinator in terms both can understand.

Chapter Two

THE GROUP HOME AND THE STATE MENTAL HEALTH SYSTEM

This chapter deals with the group home's relationship to the Department of Mental Health and how that relationship adds to the difficulty of providing community care for long-term mentally ill residents. As we have seen from the previous chapter, providing care in the community for people with long-term mental illness is a tremendous challenge even under the best conditions. It is emotionally draining for both staff and residents to form relationships, and to find ways for the resident to fit into a community that is not willing to acknowledge or accomodate his/her abilities as well as disabilities. The need for a mental health service system to support the group home in this undertaking is obvious. Rather than supporting the group home in stabilizing the client, however, DMH continues to use the group home as a means to depopulate the state hospital.

Historically, DMH has used group homes as a way to reduce the state hospital inpatient census. If a client had to return to the hospital for more than a month, DMH would pressure vendors to accept another client from the state hospital as a replacement. In DMH's view, the state hospital was not to be used as a back-up for the group home. They expected that the

group home could handle client crises internally as well as continuing to function as a "normalizing" environment for other residents.

The contradiction between an environment designed to handle crises on a regular basis, and one designed to create a home-like, normalizing atmosphere for long-term mentally ill people to live in soon became apparent. DMH began to tolerate vendors holding residential placements for up to two months or longer while the client was in the hospital recuperating from a psychiatric crisis, yet they refused to acknowledge the residences need for access to crisis intervention and respite services. Despite the fact that the state hospital continues to serve these functions, DMH maintains that crisis intervention and respite care are not a legitimate use of state hospital inpatient time.

Section 2.1 State Hospitals explores the relationship between the state hospital and the group home and shows how DMH trys to relieve state hospital overcrowding by transfering as many clients as possible to community residences. In turn, the group home trys to maintain the integrity of its program by being selective about who it accepts, and by trying to remove clients who are disruptive to the home. The state hospital and the group home work not in cooperation but at cross purposes to one another.

In lieu of other alternatives, staff and residents continue to use the state hospital as provider of last resort for handling psychiatric crises. This leads to frustration on both sides. DMH policymakers are frustrated in that group homes do little to reduce the inpatient census. Group home staff are frustrated in that state hospitals are an inadequate and reluctant source of crisis intervention and respite care services that their clients need. The unresolved conflict between the state hospital and the group home undermines the group homes ability to function and prevents the state hospital from redefining its role in an emerging system of community care.

In section 2.2 The Relationship between DMH and the Vendors, we look at DMH's overall relationship to the vendors. Unlike the clear cut conflict of interest that exists between the state hospitals goals and the group homes goals, DMH's overall relationship to the community residence is characterized by ambiguity over authority and responsibility. DMH tightly regulates some of the small details of group home operation while at the same time leaving the larger issues of client satisfaction and staff suitability to the vendor.

Staff resent DMH Central's lack of recognition of the importance of their work with clients as well as the added workload that the regulations impose. To staff, DMH

regulations have little relationship to the quality of life in the residence. The fact that these regulations are developed and administered by officials from DMH central office without input from residential staff only adds to their feelings of alienation. Staff are frustrated by their inability to influence or even understand the purpose of many of DMH's regulations.

Section 2.3 ISPs, deals with DMH attempt to monitor the quality of client care through the use of individual service plans (ISPs). These plans are meant to insure that clients are receiving treatment for every identified deficit or dsyfunction they have. Staff and administrators contend that ISPs are not a "useable" tool and that the ISP process can be destructive of the resident's self-esteem and motivation.

Section 2.4 Case Management examines DMH's implementation of a case management system. Rather than acting as a point of access and coordination of services for the client, the case mangement system, as it is presently constituted, threatens to become just another layer in already complex and disjointed service bureaucracy. Staff, vendor administrators and Area Office officials express disappointment and frustration with the case management system in its present form, and they identify some unmet client needs which case mangement could address.

2.1 State Hospitals

"We have a problem with the hospitals. We're overcrowded
and understaffed. The situation has become more acute
lately. We've got hundreds of patients on the wards who are
not our clients. Last year, we hired 500 people to work in
the hospitals. We are working to get JCAH accredidation.
We are one of the few public agencies with an emergency
intake process. DMH always ends up as the service provider
of last resort."   (DMH official, March 1988)

Almost from their inception, state mental hospitals in

Massachusetts have been plagued by the problem of overcrowding.

Worcester State Hospital, opened in 1833 as a model institution

for the care of mentally ill people through the use of moral

treatment, soon found its staff and facilities overwhelmed by

an influx of patients. Despite several expansions of its

facilities, and the opening of another state hospital in

Taunton, continued overcrowding made it impossible for

Worcester State Hospital to maintain its original high

standards of patient care. Moral treatment - "kind,

individualized care in a small hospital with occupational

therapy, religious exercises, amusements and games, and in

large measure a repudiation of all threats of physical violence

and an infrequent resort to mechanical restraints", had by 1850

been largely replaced by the use of physical restraint,

custodialism and an emphasis on maintaining order in a large

complex institution. The addition of four more state hospitals

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by 1875, did not solve the problem of overcrowding at Worcester
and Taunton and soon these facilities were filled beyond
capacity.(16)

The problem of overcrowding in state mental institutions was
due only in part to underestimating the size of the population
of severely mentally ill people in need of treatment. The
other part of the problem was that state mental institutions
came to be percieved as suitable dumping grounds for many
different types of people that the community found undesirable
or unmanageable. Mentally retarded people, immigrants,
eccentrics, orphans and paupers were all possible candidates
for incarceration in state mental hospitals. (17)

Belknap describes this phenomenon succinctly. " The opening in
1833 of Massachusett´s Worcester State Hospital marked the
inception of an extensive asylum building program throughout
the United States. Yet, new doors hardley opened before
facilities were jammed with inmates drawn from the almshouses
and jails of small towns and cities. Efforts of the early
asylum superintendents - the psychiatric leaders of their time
- to avoid this swamping of a medical institution by a
miscellaneous nad often untreatable avalanche of indigent,
deviant and mentally deficient people were frustrated. And
during this period, the character of the state hospital in the
United States, with its growing static population and

contradictions in its functions, became set." (18)

Over thirty years since the advent of deinstitutionalization in the 1950s, overcrowding and dumping remain issues for state hospitals in Massachusetts. The Department of Mental Health has struggled in vain to define an inpatient population small enough to be served by existing staff and facilities. A recent Boston Globe article reports, " Concerned that overcrowding has hampered its ability to treat chronically mentally ill, the Department of Mental Health has proposed the transfer of 25 percent of its patients to general hospitals, community residences or private centers, and says it will place a cap on admissions to all state inpatient psychiatric facilities." (19)

The persistence of overcrowding reveals that the "contradictions in its functions" which beset state hospitals in their early development, were never resolved. The state hospital was called on to provide welfare for the dependent, treatment for the mentally ill, and control of people who frightened or annoyed the community. Because the symptoms of long-term mental illness blend in with other forms of social dsyfunction: inability to hold a job or maintain housing, destructive or violent behavior, alcoholism; the state hospital system has been unable to develop clear and convincing admissions criteria which relieve the state hospitals of the functions of social control and provider of shelter.

Moreover, both the community and many long-term mentally ill people have become accustomed to using the state hospital as the provider of last resort. Community institutions in general are not prepared to respond to a psychiatric crisis in a way that adresses the long-term mentally ill persons need for consistency. Without knowing the history of the long-term mentally ill persons´ disability, and without being able to offer them the immediate relief of familiar procedures and faces, existing sources of emergency care in the community, such as the general and community hospital, are seriously handicapped in providing effective crisis intervention.

The Department of Mental Health is attempting to divest the state hospitals of many of their functions before these functions have been assumed by other institutions in the community. The number of housing placements available to long-term mentally ill people is very small in relation to the current state hospital inpatient census, and even smaller in relation to the roughly 40 percent of the homeless population who are mentally ill. (20) Emergency intake services geared toward handling a long-term psychiatric population are simply not available through community and general hospitals. Indeed, it is not clear that the most important role of the state hospital, that of coordinating the separate aspects of long-term care: shelter and welfare, treatment, and crisis intervention; will be assumed by any agency in the community.

Staff in the community residences feel the pressure from the Department of Mental Health to help decrease the state hospital inpatient census, and to take over many of the functions which the state hospital used to serve. The pressure from DMH on residences to take inpatients is manifest at every stage of the clients's involvement with the residence - entry, length of stay, and exit. When a place opens up in a residence, the Department may insist that the agency take a client from the state hospital inpatient unit, even though the staff may feel that the client is inappropriate for their residential program. Once a client is in a residence and continues to use the state hospital inpatient unit for frequent or lengthy readmissions, the Department will put pressure on the vendor to replace that client. Finally, if the residence accepts a client from the state hospital who, in the residential staff's estimation, does not work out, the state hospital will not accept the client back. Each of these pressure points - entry, tenure, and exit - represent a potential power struggle between DMH and the residence director, as criteria for admission, tenure and termination are ambiguous and as its not clear which agency has the final say.

The disagreements between DMH and the residential agency that occur over client admission are outlined by an Area Office official:

    "The original client selection is not much of a problem.
    You say to the vendor - `These are the people. Can you run

a program to serve them?´ They say yes or no. Referrals to established programs create a problem. Either the client we want to refer doesn´t fit into any of the residential programs we have, or the timing isn´t right, or the opening is available too soon or too late.

Every once in a while you get into an issue with a vendor. We had one client who we thought would fit into this residential program. On her first visit there she goes into the bathroom and smokes a joint. They said they couldn´t take her, she was a substance abuser. We said it was a one time thing. We went through some heavy negotiations and got them to reconsider. Turns out she worked out in the program."

Another Area Office official said that the pressure to take people off the ward came, not from the Area Office, but in directives from DMH´s central office to the hospitals. She saw herself as working with the residences to find appropriate clients:

"Our top priority is to move people out of the hospital. That priority really gives you a false sense of certainty since for most of our clients, it´s a fine line between being out and being in the hospital. The political climate is such though that we must maintain the illusion that we are reducing the hospital census.

They have a pool of 80 geriatric people at the hospital who are supposed to receive first consideration. Most don´t fit into the kinds of geriatric programs we have. Congregate elderly living takes a certain minimum ability to function. Many of the elderly on the ward don´t have that minimum capacity.

Rather than let the beds go unfilled, hopital staff let us take people from the community who can fit the program. Even so there are a lot of mentally ill people deteriorating in the community who could be stabilized if we had more beds. It´s heartbreaking to have someone encounter the state hospital for the first time in their seventies because you can´t find a place for them."

Both Area Office Officials express a willingness to negotiate

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with vendors to get a client that is mutually acceptable. Both recognize the importance of clients fitting into existing programs. With so many clients waiting for placement and so few placements opening up, these DMH Area Office personnel did not feel the need to push too hard for any particular client. Nonetheless, they feel the pressure from DMH's central office and at least try to "maintain the illusion that we are reducing the hospital census".

Residential staff noted the effects of DMH's drive to reduce the census in the number of inappropriate referrals they were receiving. Several staff noted that staff input into client selection had been pre-empted by agency administration, or even area office personnel. The amount of staff input on client selection varied widely from area to area, with some staff having a great deal of input and others having none at all. Regardless of the level of input, many staff felt that their program had been pressured into accepting clients who didn't fit the program's requirements or client profile.

Another pressure point, tenure, was felt far more acutely by staff as an area where DMH was working against the stability of the residential program, not for it. As one staff person said:

> "Another stress for staff is the new DMH policy which says
> if a client is hospitalized for 2 consecutive months or 6
> months total in a year, we can't hold their place for them
> in the residence. There is also another rule which limits
> the amount of hospital time all the clients in the residence
> put together can use.

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These rules really put a lot of pressure on us and them. For example, we brought Jane (a client) back in 2 months so she didn´t lose her place. She decompensated right away and went back for another two months.

Then there is Helen who was in the hospital last year for 6 months. This year she´s been in only for 2 months in 3 day stints. She´s doing much better now but all the hospitalizations add up. Clients know about this rule and it puts tremendous pressure on them."

At the same time that DMH is pushing vendors to take the tougher, more chronic clients off the ward, it is also limiting the state hospitals´ responsibility to ease the transition into residential housing for these clients. Staff feel caught in Catch 22 of trying to ease individual clients out of their dependence on the state hospital, while still insuring that the group does not get penalized for racking up too much state hospital time. One of the Area Office officials quoted previously sympathized with the staff´s dilemma:

"A real problem with client selection is that you can´t get the client back into the hospital if they don´t make it in your program. They don´t even allow you a reasonable transition period any more, where the client can gradually get used to leaving the hospital.

You may have a client who´s been in the hospital 10 years or more and they sign them up for the residential program on Friday and Monday morning they are out of the hospital, in a new residence and starting a new day program. How would any of us feel if we had to move and start a new job on the same day."

The other Area Office official previously quoted expressed surpises when I asked about the new rule capping rehospitalization time.

"I haven't heard of any limit on hospitalization time for people who are in residences. We certainly have people in our residences now who periodically have to return to the hospital for short periods to recompensate. If there is a cap on total hospitalization time available to clients in our community residences, I think we'd be in trouble. We're serving some of the most difficult, long-term clients. You can't wean them away from the hospital over night."

To understand why the hospital continues to play an important role in the lives of clients in community residences, it is necessary to understand how clients view the state hospital. A staff member describes this:

"For this client, she would decompensate by becoming threatening and by stopping grooming and cleaning herself. We would call the ambulance to take her to the hospital, and you could feel the sense of relief she had when the ambulance pulled into the driveway. She'd stop being threatening and get ready to go.

She feels safe in the hospital. When she's really out of control the hospital feels like the only safe place to be. She knows that the residence is better - the smaller setting and people are nicer - but feels that the hospital is safer when she is not doing well. It's a safety valve for clients to know that they can go back when they are not doing well."

A client in another residence corroborates this staff person's interpretation of why clients need to return to the hospital:

"I have to go to the hospital sometimes so I can't hurt myself. They have more structure, more staff, no sharp objects. I like it here. There isn't any other house I'd rather be in."

This client's comments seemed particularly eloquent as she was having such difficulty participating in the interview. She shifted in her chair anxiously and seemed out of breath. She

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also seemed to have difficulty concentrating.

When she was first asked by staff if she would like to be interviewed by me, she said no. Then when she heard the interview had to do with housing she said yes. It seemed very important to her to weather the difficulties of interviewing to get across to me her concern about keeping her place in the residence. Under the rehospitalization rule she was in danger of losing her place. She spoke most directly to me when she said:

> "What I don't like is the new rule about hospital time. They only let you be in the hospital for two months. It's scary because I could lose my place. Last year I was hospitalized for 6 months straight and they kept my bed. This year I've already almost used up my time. I can only be in for 4 more days or I lose my place. That's a lot of pressure for me."

A staff person who works with this client elaborates on what she thinks the client gets out of rehospitalization:

> "It takes the pressure off her. She doesn't have to go to her dayprogram. She can wear her headphones all day long without having to interact with anybody. The headphones stop the voices for her, but here sometimes residents run out of patience with her when she's got the headphones on all day. She feels safer at the hospital during these periods. They watch her closely, take away all her responsibility. It's a place to go when life is unbearable."

The state hospitals ability to provide safety to the residents has assummed almost mythic proportions. Clients in different residences referred to the state hospital where they came from

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by names such as "The Big House" and "The Hill". These names indicate that the safety of the state hospital is synonomous with its overarching control of the client's life. For clients who at times fear nothing worse than they fear themselves, trading self-control for safety may seem unavoidable.

Interestingly, the therapist from the private residence noted a similar tendency among her clients:

> "The hospital often feels like the first safe place that many of our clients have ever known. Like a parent, it's controlling and nurturing. Sometimes the clients want to give up the struggle to take risks in the world. It's a wish to return to the womb. We have a joke around here about wanting to go back to Mama McLean."

Another staff person picked up on the issue of safety:

> "The state hospital feels safe because its a known quantity. There are lots of external controls. There are locks on the door, people they fit in with, and staff they know from previous hospitalizations.
>
> When they start to do better, they want out of the state hospital immediately. Then the impersonal surroundings, having your things lost or stolen, and being around other very actively crazy people gets to them."

Clearly, the need exists for a place of refuge, a place of external controls, a place where reisdents can go when "life becomes unbearable". It is a testament to this need that state hospitals, grim and deteriorated as they are, still serve this purpose for clients even when they like their placement in the community.

Interestingly, clients who have managed to avoid state
hospitalizations up to this point in their lives, continue to
want to stay away from them even when they feel out of control.
Having experienced a sense of safety in a less controlling,
less impersonal environment, they have learned to rely on
private psychiatric hospitals to provide brief periods of
respite. A staff person pointed out to me that introducing one
of these clients to the state hospital system would be
destructive:

> "Those clients who've never been in the state hospital, or
> who've been in only briefly, have a very negative atitude
> toward it. It doesn't promise safety to them at all.
>
> The state hospital is a place where things are real crazy
> and a place you go when you're not doing well. They don't
> feel as bad about going to a private psychiatric hospital.
> It's a much less feared setting - no locks, lots of
> attention, regular therapy sessions, a more cheerful and
> attractive environment."

The comments of these staff people and residents raise several
issues about what the state hospital's role should be during
the transfer of treatment from the hospital to the community,
and what role, if any, the state hospitals should play in a
system of long-term care for mentally ill persons. In light of
the history of state hospitals, it is apparent that they cannot
provide both an individualized, small, comprehensive treatment
setting - "moral therapy" - and on demand crisis intervention,
evaluation and respite care to a large and varied population
with psychiatric disturbances. The two functions are

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incompatible as one deals with a small stable population, the other with a large, transient one.

DMH is moving toward restricting the state hospitals role in crisis intervention, evaluation and respite care, long before these services are readily available elsewhere, and long before patients and families who have learned over the years to rely on the state hospital as a "provider of last resort", have been weaned away from the system. The role that DMH is leaving for the state hospitals - that of providing quality inpatient care to a small but stable long-term mentally ill population - remains poorly defined. Exactly which sub-category of long-term mentally ill patients is a state hospital designed to serve?

2.2 The Relationship between DMH and the Vendors

The state of Massacusetts backed into a policy of privitizing provision of residential services. Under the Brewster consent decree (Brewster vs. Dukakis, 1978) the state was forced to move many patients from Northampton State Hospital into the least restricitive setting - community residences - within a specified period of time. The only way for the state to comply with the terms of the decree, was to purchase residential programs from vendors. Vendors could operate outside state employee and procurement regulations and thus could put together a residential program much quicker than the Department of Mental Health could.

Residential programs run by vendors under contract to DMH are more aptly characterized as semi-privitized. Though they may hire staff as private employers, and make some purchases without obtaining bids, vendors are still subject to line item budgets, monthly reporting of expenditures to the state, annual state audits, DMH inspections every one or two years, state regulations for acquiring equipment and furniture, and DMH regulations on client record keeping. The myriad regulations and reporting requirements having to do with the residence's financial, physical, and clinical status, create a hardship for vendor administrators who must divide their meager resources among client care, physical maintainence and paperwork.

One Area Office official sympathized with the vendors'

predicament:

> "Vendors don't want to deal with the state because of the
> incredible amount of bureaucratic red tape. Paying people
> for overtime is a big production. Every time you want to
> make a little change in your program it's a lot of work.
>
> We are constantly juggling funds to meet our end of the
> contract. Sometimes, if we don't have the money, we'll give
> them a state employee to fill one of their positions
> instead. This creates a whole other set of problems for the
> vendor. Now they have two employees working side by side,
> doing the same job and getting paid different salaries.
> Also the state employee is covered by the union and their
> employee isn't. It creates a lot of bad situations.
>
> I just put out an RFP for an SRO we want to start. I got
> one bid back. There are three vendors who could've bid on
> it. I guess the other two just weren't interested."

A vendor administrator in another area of Massachusetts

supports the Area Office officials viewpoint:

> "The whole way the Department contracts for services is
> terribly burdensome. We get very bogged down by all the
> information we have to provide to the state. It's an
> antiquated way to run a system this big.
>
> Administration and Finance brought in a consultant to look
> at the way state human service agencies contract for
> services. The consultant concluded that far too much state
> time and money was spent monitoring things that had nothing
> to do with the quality of the services provided. He
> recommended paying vendors a flat fee and letting us use our
> disgression on how to allocate it. He said the quality of
> the services should be monitored, not the details of the
> budget.
>
> I think we could provide more and better services to our
> clients if we didn't have to do all this record keeping. I
> think the regulations help keep the mediocre vendors in
> business. They can survive by filling out the right forms,
> never mind about serving the client."

It is not only vendor administrators who feel that their

ability to do a good job is being hampered by the welter of
regulations from DMH. Staff also express dismay at the number
of counterproductive, or simply bothersome regulations that
emmanate from the Department:

> DMH has been putting a lot of pressure on our vendor which
> in turn translates into more pressure for us. DMH wants
> consistent regulations. So now programs that have been
> working well have to change in order to be consistent.
>
> I always feel like I'm not getting the full picture because
> I can't make sense out of what DMH is doing. For example,
> licensing - all they look for is fire hazards. They never
> ask how clients feel or how they are doing. Things that I
> feel are the essence of the program, they don't even look
> at.
>
> It would be easy enough to give clients a questionaire,
> maybe multiple choice, so the DMH people could get some idea
> of client satisfaction. They just don't seem interested."

This staff person's comments highlight two issues that were
frequently cited by other staff: DMH's drive to standardize
programs as a way of monitoring them, and the tenuous, or even
inverse relationship between DMH regulations and program
quality.

The following comments by a staff person in another program
illustrate this:

> "DMH has a lot of regulations that are both very specific
> and constantly changing. It's hard to keep up with what
> they'll require next. The licensing inspections are
> incredibly picky. We have to go around every year cleaning
> out the heating ducts because they have some rule about dist
> in vents. Personally, I'm not even sure where the vents in
> my apartment are and I've lived there for two years.
>
> I can't understand why they do it so strictly. Before I
> worked here, I worked at an adolescent residential program

where conditions were pretty bad. It was an old run-down house and the landlord refused to fix anything. Staffing was low - a lot of times I was the only one on. Record keeping was bad. They inspected it but they never pulled the license. The only way it closed down is when the contract came up for bid,they awarded it to another agency.

Personally, I think you can see a spotless house on inspection and still have the worst program. I think the client/staff relationship is the heart of any program."

Another staff person commented:

"DMH regulations are burdensome. When you're already overworked, all the record keeping and paperwork and the preparation for licensing inspections are too much. Residential programs have gotten more and more regulated over the years. This place is understaffed and all the regulations do is take time away from client care.

Some record keeping is helpful and I don't begrudge doing it. We write notes on every resident twice a day, and each shift writes a report about things in general to the next shift. Records that help us take care of the clients I don't mind at all."

Staff, who work very hard, often against great odds, to maintain long-term mentally ill residents in the community, feel that DMH regulations just make it harder for them to hold onto their clients. They are bewildered by this as their goal, to keep clients in the community, and DMH's goal are supposed to be one and the same. Like the staff person quoted earlier, many feel that they are "not getting the full picture, because I can't make sense out of what DMH is doing." One staff person spoke at length about his frustration with not understanding DMH's role in running the community residence:

"I wish I knew more about the mechanics of client selection. I would like to know what DMH's role is in all of this and

how does that affect us? How much say do they have? I do
know that it's up to the vendor to run the program as they
see fit, but then these rules seem to pop up out of nowhere
and suddenly DMH is in the picture again.

It's important no matter what level you're on in an
organization to know what your business is about. In my old
job, I knew how what I did contributed to the final product.
Here I sorta feel like I'm operating in a black box.
Sometimes I feel I don't know everything I need to know
about DMH in order to do my job well.

I knew where I fit into the picture in my old job.
Politically, I knew how it was, who was in charge. I have a
hard time with the politics here. You need to get along
with everyone because it seems like almost everyone is
capable of holding up your client. I don't know who has the
final say.

Once we had a client here who was placing the house in
turmoil. The director of the residence couldn't get rid of
her. It doesn't seem right that the director can't make
that decision. I suppose if you had an incompetent
director, you wouldn't want them to make that decision, but
then you should be worrying about getting good directors,
not tying up all your residence directors in case one of
them is incompetent.

Whenever there's a problem with a client you have to call
everyone in on it: the day program staff, the residence
staff, the vendor administrator, the case manager and the
Area coordinator. You have to get everyone to agree or
nothing gets done."

This staff person's comments pinpoint a central question that

has remained largely unresolved during the transfer of care

from the state hospitals to the community residences: who is in

charge? This question remains unanswered in part because of

the underfunding of the mental health system. If there is not

a sufficient supply of certain vital services for the long-term

mentally ill, no one wants to be held responsible for not

providing those services. Ambiguous lines of accountability

help camouflage the fact that services are simply unavailable,
by diverting attention from meeting the clients needs to the
decision making process around meeting the clients needs.
Since any of the parties to the decision can "hold up" the
client, it appears that it is the lack of concensus, not the
lack of services, that prevents the client from receiving
treatment.

The other reason why the question of who is in charge remains
unanswered is due to the large element of unpredictability in
long-term mental illness. When clients don't get better,
despite treatment, there is a tendency to want to assign blame.
Not so long ago, mental health professionals blamed families
for the lack of client improvement and even for causing the
disease. Today it is more socially acceptable for mental
health professionals to blame each other for mishandling the
client's case. Instead of acknowledging the unpredictability
of the disease, and thus the limits of professional expertise,
it is tempting for mental health professionals to cite others
involved with the client as the source of the clients
deterioration.

At the very least, involving many mental health workers in the
decisions on client care limits everyone's liability. This is
one way to minimize the risk involved in making decisions in
situations that have a good deal of unpredictability.

Lack of services may explain DMH's slowness in closing down the substandard adolescent program that the staff person refered to earlier, despite regular licensing inspections. As an Area Office official said in her interview:

"The relationship between DMH and the vendors is funny in a lot of ways. A lot of times they have us over a barrel. If they don't live up to the terms of their contracts what are we going to do? A lot of times the vendor is the only game in town. We don't have any sanctions. You can threaten all you want but when it comes right down to it, you don't want to close the program unless its bad. What would you do with the clients?

You try to have some overall sense of how well the vendor is doing aside from this or that detail of the contract. Like one of our vendors is dealing with some very difficult clients and managing to keep them in the community. So they're not getting their paperwork in on time. You cut them some slack and say look at the clients they are holding on to."

2.3 Individual Service Plans

It's a DMH regulation that each client in a community residence must have an individual service plan. This service plan is developed by the resident and a staff person when the resident moves in. The plan should list the residents short-term and long-term goals, and include a detailed account of how the resident expects to reach those goals. The plan is reviewed and updated every three months.

ISPs were derived from the type of treatment plans used in programs for the mentally retarded. ISPs however lost a lot in the translation from MR to MH programs. The deficits of longterm mentally ill people are emotional and social, not cognitive and physical. Their treatment consists of learning to accept that they are mentally ill (i.e. that the voices are in their head and not really broadcast over the radio), and learning how to manage that illness so as to be able to engage in interactions and activities. This kind of learning can only take place in the context of a stable, trusting relationship with a staff person, therapist or other person in close, daily contact with the client. This learning is not the product of practice or routine but the result of the constancy and the caring of the staff person demonstrated to the mentally ill person in many different situations over time. It is not the kind of learning that can be scheduled into an ISP.

DMH uses the ISP to insure vendor accountability for providing treatment for the resident, as opposed to letting the resident just live in the residence without working on any of their disabilities. DMH officials participate in yearly ISP meetings with the staff and the resident, at which time they give their input and/or approval of the initial ISP, and receive updates on the resident's progress toward achieving ISP goals. ISPs are also reviewed for completeness during DMH residential licensing inspections.

The individual service plan covers every aspect of a resident's life from smoking habits to personal hygiene, to relationships with friends and family to history of psychiatric hospitalizations. The resident, with the staff person's help, is expected to write down how they will make improvements in each area of their lives, and how those improvements will be readily apparent to staff, case managers, social workers, and other DMH officials who have access to these records.

Staff in several residences brought up the ISP spontaneously. Their comments illustrate that staff and residents view the ISP as an invasion of the resident's privacy and not just as a benign way of recording the resident's progress:

> "Now they tell us that case managers are going to be doing the clients' ISP. Now we don't ever hide the fact from our clients that they are mentally ill. Our whole atitude is that `Yes, you are mentally ill, but that's no excuse.´ But coming to grips with mental illness is painful and something that they can only do over time with someone they learn to

trust.

For example, we´ve been working with a client for a long
time now to try and get him to admit that he hears voices.
He says he can´t talk about them because they say they will
kill him if he does. Can you imagine a case manger who
doesn´t even know this client, calling a case conference of
all the people who work with the client, and the client
himself, and publicly running down the list of this clients
problems and goals as if they were a laundry list?

I think its callous and insensitive. What´s more, there is
no therapeutic philosophy behind it. What possible good is
it supposed to do this client to hear his problems read out
in front of everybody.

When staff make a rule in this house, we explain ourselves
to clients. There has been no attempt to explain the
purpose of this procedure to us or our clients"

A staff member in another house also brought up ISPs:

"I really don´t like the ISPs. Once a year we write up with
the client their plans and goals for the coming year. Then
every three months we are required to sit down with the
client and review it. The residents detest the whole
process.

It´s infantilizing to ask someone to write down their life´s
goals and report to you on them every three months. It
feels to the resident like somebody out there, running their
life. It takes control away from them.

If anybody came up to me and said I had to write down my
life goals for the next three months and let others look
them over, I´d tell them to mind their own business.

If residents could control the process and use it as a way
to monitor their own progress it would be different. The
way it is now, its just someone imposing more rules on their
life."

Staff adjectives like "callous", "insensitive", and

"infantilizing", indicate that the ISP is not just another

bothersome batch of paperwork, but a practice that runs counter

to staffs´ whole concept of how mentally ill people should be

treated. They feel that the process trivializes their clients´

suffering, and insults clients´ intelligence. The ISP process

assumes that the client is unaware or insensitive to the

failures in his/her life, and has no compunction about

acknowledging these failures publicly to mental health

officials they hardly know. Presumably, if clients were that

inured to their failures, ISPs would have no motivating

potential for them anyway. As the first staff person quoted

above noted, "there is no therapeutic philosophy behind it".

An Area Office official was blunt in her assessment of ISPs,

even though, as a representative of DMH, she is required to

monitor them:

> "I hate ISPs. I think it´s a nice idea in theory, but it
> just doesn´t work. I don´t see how you can write a
> behavioral plan for a mentally ill person. The whole
> wording of the ISP document is ridiculous. You end up
> writing a plan to satisfy the ISP regulation and it has
> nothing to do with the client it´s written about. It´s just
> not a usable tool.
>
> It´s difficult to get vendors to do ISPs. It´s not that
> they outright refuse to do them. Instead they use delaying
> tactics and excuses, saying they will get to them
> eventually.
>
> After all, they agreed to do the ISPs in the contract they
> signed with DMH. However, when the contract is up for bids
> is no time to tell DMH they don´t like ISPs. It´s a sort of
> Catch-22 that keeps everybody pretending they´ll get to the
> ISPs eventually."

An SRO administrator picks up on the Area Office official´s

observation that a behavioral plan is inappropriate for

mentally ill clients:

> "ISPs use this behavioral model that MR programs use. That
> doesn't work for our clients. You need a program specific
> treatment plan.
>
> The way ISPs are run now is so demeaning to the client. A
> lot of the way we work with clients in our program is to
> encourage them with verbal praise. To write that down -
> `client will receive reinforcment through verbal praise.´ -
> destroys the whole process. It makes you seem insincere to
> the client and it gives them the wrong message.
>
> They´re not supposed to be doing things to please staff, but
> to build up their own self-esteem. Staff are really trying
> to help them get to their own sense of self-esteem. We´re
> trying to build a relationship with them, not interact
> according to some reinforcment schedule.

The SRO administrator went on to say that in her area, DMH case

managers are responsible for actually writing the ISP. She and

her staff work with clients using a treatment planning

checklist. She describes how their approach differs from the

ISP process:

> "We don´t do the ISP ourselves but contribute to it by doing
> a treatment planning checklist. When clients first move in,
> we give them a form which lists all the different areas of
> their life they can choose to work on. A lot of the things
> on the form are really tough problems to work on. You can´t
> possibly work on more than one or two at once.
>
> It´s as if somebody started you in a program and said,
> `O.k. now, in the next 3 months you´re going to quit
> smoking, lose weight, start exercising, make 3 friends,
> enroll in school, and on and on. Normal people can´t take
> all those drastic changes at once, yet DMH expects mentally
> ill people to do it. Thats why the ISPs are so ridiculous.
> The client has to list every single thing that´s wrong with
> them and how they are going to work on it.
>
> We encourage clients not to look at everything wrong with

them. When we give them the treatment planning checklist, usually every client checks off "quit smoking". They do it to get staff's approval. When they find out it's not a requirement and we won't hold it against them, they take it right off the list.

We encourage clients to be honest, to tell us what they really want to work on. There is another form we fill out that has a column for "current status" of the residents' progress toward their goals. We divide that column in half and let the staff write down their opinion of the client's current status in one half, and let the client give his own opinion of his current status on the other half.

In most other programs, when the client meets with the staff person to develop the ISP, the client gives his opinion, and the staff person just writes down what he or she thinks."

This SRO administrator goes on to tell a story that illustrates

both how she and her staff try to neutralize the destructive

effects of the ISP process, and how one client dealt with the

pressure of an ISP meeting:

"As I said, the case manager from DMH is in charge of the ISP. We are a little apolegetic to our clients about the whole scene. We say, `Well look, it's a requirement for us, but if you don't like how you are being treated, you can walk out.´

How the ISP meeting goes usually depends on the personalities of the people involved. Some case managers are more sensitive than others.

We had one woman client who did really well throughout most of the ISP meeting. I was surprised at how well she held it together because she's usually really scrambled. But they kept at her about did she know she needed to do this, and how did she plan to accomplish that, and after a while they dropped her out of the conversation altogether and began talking about her.

Near the end of the meeting, my client got up and said very clearly but in a very shaky voice, "O.k. now, you ladies are much too boring for me. I'm leaving."

Clearly, there are alternatives to the ISP for measuring

resident progress and encouraging them to work toward improving

their lives. Residential stability, in and of itself, usually

marks a major improvement in residents lives. As the SRO

administrator concluded:

> "We measure resident progress in terms of how long they've
> been able to stay in the residence. We have a lot of
> clients now who have been in the program three years, and
> some for two years. These are the same people who were
> constantly getting evicted out of other residential programs
> and apartments, and spending long periods in the state
> hospital in between."

The ISP model is based on the premise that through constant

monitoring, long-term mentally ill clients can become fully

functional again in all aspects of their lives. It seems more

likely that the opposite is true. ISPs raise false

expectations about what residents can accomplish in a given

period of time and therefore put a lot of unnecessary pressure

on residents and staff. Staff feel that they're not doing a

good job because residents are not achieving according to

schedule. Residents are confronted every three months with

their failures. Most importantly, the relationship between

staff and residents is damaged by forcing them both to

participate in a process which they believe is demeaning to the

resident.

Paradoxically, for the long-term mentally ill person, stability

is progress. The primary goal for most long-term mentally ill

people is to modulate the behaviors and emotions that interfere with their ability to interact with others and to take care of themselves. The goal is not so much to acquire skills as it is to, as one staff person put it, to "gain confidence in the experience of being well". The ISP´s emphasis on demonstrating change or improvement in the residents contradicts a more important goal which is to allow the residents to experience stability.

2.4 Case Management

>"The case management system is supposed to coordinate the hospital and the community. Right now we have 200 case managers. We need to get up to about 500 or 600 to have enough to really follow clients through the system. The case management system, when its fully staffed, should provide continuity."   (DMH Central Office official 3/88)

DMH's initiation of a case management system was a recognition of the fact that the service needs of long-term mentally ill people vary greatly from client to client, and within the same client over time. Case management was an attempt to individualize service delivery in response to the unpredictable course of long-term mental illness.

Unfortunately, DMH's case management system was grafted onto the existing balkanized system of service delivery in which access to, operation and oversight of, the various mental health services is in the hands of many different sovereign and competing parties. Vendors, Area Office officials, state hospital personnel, and officials in widely scattered offices within DMH central, all control a small piece of the service pie. Moreover, even within any one service, such as residential placement, control of the access to, and operation of, that service is shared uneasily and ambiguously among many of the players in the public mental health system. Given this kind of fragmentation of responsibility and control, the case manager has little ability to deliver services of any kind to

the client.

In addition to the unresolved issues of control and access in the case manager's relationship to the mental health service system, DMH's case management policy also leaves the nature of the case manager's relationship to the client very much in question. How is the case manager to determine which services the long-term mentally ill client needs and doesn't need? Since, according to DMH's policy, case managers are supposed to be non-clinical, who's assessment of the client's condition are they supposed to accept - the residential staff's? the state hospitals? And if case managers are basing their treatment plan on someone elses assessment of the client's functioning and needs, why not let the other party access those services directly for the client? What is the advantage of interposing the case manager between one service provider and another?

In theory, the job of the case manager is to be a "broker" of services for the long term mentally ill client. As service broker, case managers are to 1) put together a package of services tailored to meet the needs of their client, 2) make sure that these services are consistent with each other, and with the client's overall treatment goals, 3) follow the client over time so as to become thoroughly familiar with the client - his/her strengths and weaknesses, preference, patterns of service use, family situation, etc. - and thus be able to help

service providers make informed decisions, and 4) follow the client over time so as to become thoroughly familiar to the client. In this way, case managers can serve as a point of access to services for clients who's disability makes them incapable of using the normal bureacratic channels of service delivery. (21)

To fufill these four functions of case management - acquiring services, coordinating services, keeping complete client records, and serving as a point of access for the client - the case manager must have a certain amount of leverage with both the service providers and the clients.

Under the present DMH case management policy, case managers have little if any leverage in their relationship to service providers. The vendors, those agencies that provide services under contract to DMH, negotiate their contracts with the Area Office according to regulations from the Central Office. Vendor contracts are monitored by two separate offices within Central Office: licensing and contracts ; as well as being monitored by the Area Office. There is no provision in contract negotiations for case manager input, no mechanism for case managers to withhold funds from programs they believe are not serving their clients.

The intermixing of Area Office and Central Office

responsibility in negotiating with and monitoring the vendors, make it unclear who is responsible for the overall quality of the services which the vendor provides. Given DMH´s present piecemeal approach to insuring vendor accountability, in which one office is reponsible for one aspect of a program, another office is responsible for a different aspect, the ability of a case manger to have an impact on the way vendors operate their services, is very limited.

The case manager is also strictly limited in his or her ability to acquire DMH operated services for the client, and to follow the client across all DMH service settings. For example, during state hospitalization, the client is removed from the case managers case load and transfered to the hospital social worker. This practice contradicts the principle of continuity of care.

Moreover, case managers face the same stringent controls on rehospitalization that vendors face, and thus are in no better position than the vendors to secure acute hospitalization or emergency intake. Nor is the case manager likely to be able to transfer clients among vendors as there is a shortage of slots at every functional level from the lowest to the highest.

There is also no provision in DMH´s case management policy for allowing case managers to purchase psychiatric services outside

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the publicly funded system. Allowing case managers to go outside the system for services would give them more leverage within the system by letting case managers trade with vendors - removing an inappropriate client from their program in exchange for the vendor taking another client from the case load. This trading could create the client flow necessary to move inappropriately placed clients.

Given the case managers lack of leverage in acquiring services from vendors, from DMH, and from the private sector, the goal of case management of providing a comprehensive set of services, tailored to the individual clients needs, is unrealizable. Case managers have been put in a position of great reponsibility and very little authority, a situation which inevitably will lead to great frustration for them and the clients they are supposed to serve.

Turning to the case manager´s ability to fufill the functions of becoming familiar with and to the client, the basis for their ability to advocate on behalf of the client, the DMH case management policy does not address how this kind of familiar relationship between the client and the case manager will be developed. One of the most important features of the case management system, in theory at least, is that it engages in services clients who might otherwise slip through the cracks because of their non-compliant behavior or lengthy, complicated

and disjointed psychiatric history. Engaging non-compliant

and/or disorganized clients in services requires clinical skill

and plenty of time to get to know clients on their own terms.

DMH case management policy, on the other hand, emphasizes

administrative skills and efficient disposition of cases.

The case management system, with its reliance on individual

case managers as the point of coordination and continuity

between the client and the service providers, is a recognition

of the fact that long-term mentally ill people are much more

likely to connect with a familiar person, than to be able to

connect with an undifferentiated service bureacracy. DMH,

however, has reversed the logic of case management theory by

making case managers, not a point of contact, but merely

another layer in an already complex service delivery system.

Staff and administrators in community residences express

frustration, disappointment and exasperation with the way DMH

has instituted the case management policy. They see it as

another lost opportunity for the state mental health system to

become more coherent, as well as a lost chance for their

agencies to get help in obtaining services for their clients.

One staff person began to discuss the case management system

positively but without much enthusiasm. Noticing the

discrepancy between her words and her tone, I asked if case

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management was helpful to the residence. She then expressed at length her frustration with case management services:

"We get all our clients from the state hospital. Case managers make it easier to negotiate another placement if the client doesn't work out. They don't see things from a totally financial point of view. They try to take into account the client's clinical needs.

No they're not helpful. Case managers just make more work for the program staff. They just add a middleman to the process making doing anything about a client slower. Now instead of making one phone call about a client, I have to make two.

Each case manager has 50 cases. They just can't be familiar with whats happening to a client clinically. Also, case managers don't do things to help us. We've just been through an incredible battle trying to help one of our clients stay on SSI. Case managers could handle that kind of administrative stuff for us. When I tried to involve the case manager in the SSI case she said, "We don't know how to do that yet." Maybe once they get the system straightened out it will work. But in its first year, its a mess.

It's like everything DMH does. First they implement it, then they tell you about it. We're never consulted in the planning stage.

Now they have this new case management system and case managers are supposed to be non-clinical. They don't work with the clients. Sometimes they don't even see the client. Yet they're supposed to tell us which services the client needs and doesn't need. How can they possibly know what services the client needs if they don't know how the client is doing, or how they have been doing over the past year."

It's interesting to note this staff person's comment that, "We're never consulted in the planning stage." Not only does it underline the uneasy relationship between DMH and the vendors, it also highlights the issue of who best understands the needs of the clients - the staff who work with them on a daily basis, policy maker's in Central Office, or Area Office

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personnel who are only indirectly involved with clients. Of
equal importance is the question of why there is so little
communication among the various levels in the state mental
health system. Ironically, case management, which was
introduced to improve coordination and communication among the
various levels of DMH´s service bureaucracy, is distorted from
the start by being appended to an existing system of top-down
management.

An administrator at another vendor lends support to the views
of the staff person quoted above. She too sees case
management´s involvement with residential clients to be either
useless or counterproductive:

> "I think it would be fine to have case managers for
> community clients who are not in a residential program.
> People who are not hooked up to any services may benefit
> from case management.
>
> But for people who are already in residential services, case
> management´s a waste of time. We take care of making sure
> our clients are referred to the services they need. Putting
> a case manager on just means getting one more signature on
> the referral slip.
>
> I think case managers are over-worked and under-paid and
> they just started. With 50 cases to manage what can they
> do? If the client´s already in services they don´t need the
> case manager, and if the client´s not in services, I don´t
> see how the case manager is going to be able to get them
> into them.
>
> Maybe if they acted as advocates for SSI and foodstamps, or
> helped clients get or keep a place to live - that would be
> valuable. But they´d have to get more involved, like making
> home visits, counting the burn holes in the rug to see if
> the client´s being careless with his cigarettes, making sure
> the client pays his bills, talking with the landlord - that
> kind of thing."

This administrators comments, like those of the staff person
quoted before her, call for case managers to either become more
or less involved. Case managers could confine themselves to
the task of handling bureacratic hassles for the residence
staff, like fighting for SSI or obtaining food stamps. Or case
managers could become just like a regular social worker: out in
the community on a daily basis working with clients who have no
one else to supervise them, doing everything from buying
groceries to placating landlords in an effort to keep their
client out of trouble. For the case manager to opt for either
of these roles, however, would mean abandoning the concept of
the case manager as a coordinator of a continuum of mental
health services.

The need for someone outside the residence to coordinate
services for the client is not lost on staff and community
residence administrators. They are, however, skeptical that
DMH is willing to endow the case manager's position with
sufficient flexibility and clout to make such coordination
possible. In lieu of what they believe is unattainable ideal,
someone who can work the DMH system to the client's advantage,
staff and administrators are willing to settle for giving the
case manager something useful to do.

An Area Office official's comments indicate that using
community residence staff as case managers still leaves many

gaps in the service system:

> "There is a serious problem because we don´t have case managers in this Area. Residential staff act as case managers when the client is in the residence. When the client leaves the residence, there is no follow-up.
>
> I think that´s outrageous, particularly when we have an elderly client who´s been in our system for years and we have to just dump them in a nursing home because we can´t handle them anymore.
>
> In one case, we had to put one of our clients in a nursing home 40 miles away. It´s a little ridiculous to have our staff follow a client that far away. We´re trying to work out a way to get a case manager for a client who leaves our Area. We´re not having much luck."

The lack of follow-up with long-term mentally ill clients is another of the problems that case management was supposed to remedy. Not only were case managers supposed to provide follow-up across services, and over time, but presumably there should also be some mechanism for case managers to transfer client care across geographic distance. This issue of transfer of care from one area of the state to another is not, however, discussed in DMH´s case management policy.

In practice, once a client leaves the state hospital or the community residence, the case manager´s responsibility to follow them ends. Case management, as narrowly conceived in DMH´s policy, seemeds to be focused on getting and keeping clients out of the hospital, not on maintaining client contact with appropriate mental health services.

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As one vendor administrator noted:

"DMH's focus on the most disturbed population limits our
agencies ability to do follow-up care, that is to follow
people who are not quite ready to be on their own in the
community, but who could probably make it with some
supports.

I suppose, theoretically, this contributes to the revolving
door problem, but practically, I can't say for certain that
it does. These people (former clients now in the community)
just disappear. Whether they're making it anyway, or back
on a ward, or on the street, I couldn't say for sure."

This lack of case management follow-up beyond the community

residence belies case managements stated purpose of bridging

the gap between the hospital and the community, and may

contribute, as the administrator quoted aboved mentioned, to

the high rate of readmissions to the state hospital of ex-

mental patients.(22) Most importantly, lack of follow-up

denies many long-term mentally ill people the chance to make

progress by building on past successes in treatment.

The need for coordination of mental health services is based on

the fact that many long-term mentally ill people do not

progress in a straight line through the mental health system,

but experience periods of progress alternating with periods of

deterioration. Even mentally ill people who have been stable

for many years may, through an unfortunate combination of life

stresses, experience a severe set-back. The mental health

system should be prepared to handle client deterioration

without jepardizing the client's chances to regain previous

functioning. This means allowing clients to move both forwards and backwards through the system without penalty, and to move out of the system completely without losing access.

The following quote from a staff person illustrates why this kind of flexibility in the system of long-term mental health care is necessary in order for clients to be able to progress:

> "Whenever a client wants to move on, it's frightening to the families. They worry, realistically, that a client might not make it at the new higher level and will revert back to a lower level than before. Sometimes families would rather not gamble the gains the resident has made so far. But it's not the families decision.
>
> It would be better if we could at least offer a safety net in the form of easy access to rehospitalization if necessary, and a guarantee of re-entry into the residential system. The way it is now, a resident often risks losing everything if they try to move up."
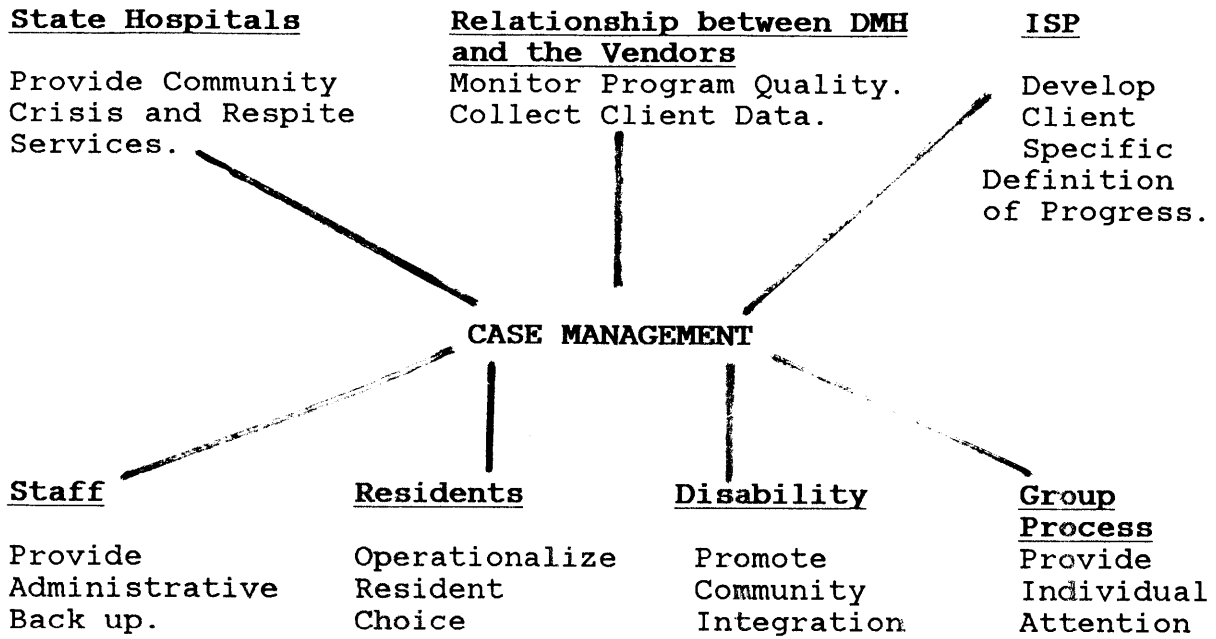
CONCLUSION

In this thesis, we have looked at how the long-term mentally ill person lives within the group home, and how the group home functions within the state mental health system. Thus this thesis has been a view of the state mental health system from the bottom up, based primarily on the opinions of the group home residents who the system is supposed to serve, and the opinions of the direct care staff who deliver residential services. This view raised many questions about how to relieve some of the pressure on the relationship between staff and residents in the group home, and how to improve the relationship between the group home and the mental health service system such that both were working together to promote client satisfaction and stability in their residential placement.

In this conclusion I will summarize my findings, and consider ways in which a well designed and implemented case management system could improve the functioning of the group home internally and in relationship to the state mental health system. I will suggest ways in which case management could help the state mental health system become more responsive to the needs of the long-term mentally ill client.

Case management has been described as "the glue that binds otherwise fragmented services into an arrangement that responds to the unique and changing needs of the patient."(23) How well that glue works is a function of the case managers ability to accurately assess client need, and to address client need by acquiring the necessary services. The case manager must know both how to work with the client and how to work with the system. The value of a case manager lies in his/her ability to do both at the same time. Without the relationship to the client, the case manager would be another service system administrator trying to deliver generalized services to the client population. Without the relationship to the service system, the case manager would be more like a therapist, able to understand client need in detail, but unable to manipulate the service bureacracy to get that need addressed. To be effective, the case manager must be a therapist/administrator.

The following chart illustrates the central position case management should occupy with respect to assessing and addressing client need. This chart outlines how a case management system could deal with some of the issues raised in the previous two chapters:

State Hospitals

Provide Community
Crisis and Respite
Services.

Relationship between DMH and the Vendors

Monitor Program Quality.
Collect Client Data.

ISP

Develop
Client
Specific
Definition
of Progress.

CASE MANAGEMENT

Staff

Provide
Administrative
Back up.

Residents

Operationalize
Resident
Choice

Disability

Promote
Community
Integration

Group Process

Provide
Individual
Attention

In the remainder of this conclusion, I describe the issues outlined in the chart above in more detail, and I examine case managements potential to address them. I also discuss the guiding principles for establishing an effective case management system, and some of the dilemmas that system will face.

Staff burnout is the result of many factors: low pay, lack of status, rotating schedules and emotionally demanding work. In section 1.1 The Staff, we examined one particular aspect of burnout that is unique to the job of staff person in a community residence for long-term mentally ill people: the

staff person's ongoing dilemma over when and how to set limits on the long-term mentally ill person. This dilemma is the result of the longterm mentally ill person's fluctuating ability to act autonomously versus his/her need for guidance and external control in order to feel safe. Staff have to switch back and forth between the roles of limit setter and live-in companion, all the while wondering if they are being too controling or if they have compounded the resident's anxiety by not acting decisively enough. The limit setting dilemma is further exacerbated by the intimacy of living with clients which blurrs the professional/personal distinction, and by the residents' lack of close relationships outside the group home which makes them extremely needy of staff attention and approval.

One way to reduce staff and residents' tension around the process of limit setting is to decrease the social isolation of the group home. Social clubs for residents to go to, therapists, case managers, vendor administrators and residents' friends and family visiting on a regular basis would all help to eliminate the sometimes claustrophobic quality of living and working in a group home. More relief staff and a higher staff/client ratio would also help. In general, relying on in-house staff to provide most of the residents' social interaction leads very quickly to burnout.

The limit setting dilemma, however, should be recognized as an inevitable part of forming a close relationship with people with long-term mental illness. Poor impulse control, volatile behavior, difficulty distinguishing between self and other, and self destructive behavior in the long-term mentally ill person all require a staff person to step in and temporarily take control of the situation. Unwillingness to take control in these situations signals, not respect for the long-term mentally ill person's autonomy, but neglect, and it only contributes to the client's social isolation.

One of the most valuable aspects of group home living is that staff are willing to assume the burden of taking control under conditions of great uncertainty. Of equal importance is staff's commitment to continue to encourage residents to exercise self control. To remain open to the two possibilities at once: of either taking control or of fostering independence, is at the heart of the limit setting dilemma. Staff are often pulled in two directions at once and must decide on the basis of very little information which way to go. Consequently, staff experience a lot of self doubt about their interventions.

The temptation exists to try to resolve the limit setting dilemma by as Schon puts it "shaving off one of the horns of the dilemma", that is by operating the group home on the basis of either promoting autonomy or providing control.

Interestingly, the two group homes in this study that seemed to function most smoothly had gone to either of those extremes: one giving residents a lot of freedom, the other structuring the residents´ day in matters large and small.

The other two group homes in this study were experiencing more turmoil. They continued to try to juggle the residents´ need for autonomy with their need for control. These two disrupted group homes also handled the more difficult clients: clients with a long history of state hospitalization, and clients who were more symptomatic. It appears the more seriously mentally ill the client, the more acute the limit setting dilemma will be, as it becomes more of a struggle for staff to find opportunities for the client to act both autonomously and safely.

Staff´s willingness to engage in the limit setting dilemma, to not give up on residents´ potential to become more self directed and more able to participate in relationships on an equal basis, is part of the "unreal" quality of group homes. As the therapist from the private residence noted, many clients don´t get the opportunity to form relationships in the "real" world because people don´t have the time or the patience to deal with long-term mentally ill people´s suffering and irrational behavior. The group home can create a sheltered environment in which people have the time and the patience and

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most importantly, the commitment to form a caring relationship with the long-term mentally ill person. That relationship can then become the bridge to other relationships in the "real" world.

The case manager can also work at developing a relationship to the resident that acts as a bridge to normal relationships with other people in the community. Case managers should have experience working with long-term mentally ill clients and a small enough case load to insure that they have the time and the understanding to build this kind of relationship. In this way, case managers can relieve some of the pressure on the relationship between the resident and the residential staff.

In addition, case managers can remove the burden of administrative work from residential staff by, as some staff and vendor administrators suggested, being responsible for getting the resident food stamps, SSI, Medicaid and other social welfare entitlements.

Case managers can also help the residential staff by keeping track of the resident's current status and therefore helping staff to anticipate or even avoid a crisis for the client. Several staff mentioned that residents sometimes have problems in the workshop or the dayprogram, that residential staff don't hear about until after the resident has begun to decompensate

or resist leaving the house during the day. Conversely, staff in the workshop or day program know little or nothing about the stresses taking place in the client's life outside the program. Case managers could provide some of the cross referencing that may make the client's behavior intelligible to direct care staff.

Often group homes err on the side of neglecting individual need. As discussed in section 1.2 The Residents, residents rarely get the opportunity to interact with the community on a one to one basis. Community activities such as grocery shopping or movie going are most often done as a group. This kind of group interaction with the community does nothing to counteract community prejudice against people with mental illness, and does little to fufill the clients need for "TLC". Unfortunately, the low level of staffing in group homes often make group activities the only option.

Residents expressed dissatifaction with having no choice as to where, how and with whom they lived. Most residents were faced with the dubious choice of group home, state hospital ward, or street. No one interviewed even had the choice between one group home and another. To call group home placement under these conditions "voluntary" is to stretch the meaning of the word beyond recognition.

To give residents a real choice in where they live means two things: drasticly increasing the number and type of community residences, and developing the information and procedures necessary for residents to make an informed decision. Speed in implementing state mental health housing development and acquisition plans should be a top priority.

The other issue in giving clients more choice in where and how they live, is helping clients make an informed decision. Because of the stigma of mental illness, and because of the denial that often charaterizes long-term mental illness, clients may opt for the most "normal" housing situation - living by themselves in an apartment - even when that situation has failed repeatedly in the past. Or housing options may be limited by the clients income, or as is most often the case now, by lack of openings in existing community residences.

Informed choice means that the case manager working with the long-term mentally ill person explains to him/her why his/her housing choices are limited and not couch the economic reality in therapeutic terms, as for example by saying a group home will be better for the client, when in fact the group home is the only housing option available. The case manager should also make every effort to elicit the client's opinions about the type of housing he or she wants. Then the case manager should be directed by the spirit if not the letter of the long-

term mentally ill person's housing ideal and refer him/her to the available housing situation that most closely approximates his/her wishes. Finally, it is important that the long-term mentally ill person be given some choices and a chance to visit each potential housing placement, and to discuss the advantages and disadvantages of each with his/her case manager. The case manager, through his/her work with many other clients in the Area, should be familiar with the various housing placements, and thus be able to help the client come to a decision. In short, informed choice means that every effort is made to make the housing placement truly voluntary.

Section 1.3 <u>The Disability</u>, showed how the disability of long-term mental illness is exaggerated and misunderstood by the community. These atitudes only add to the residents' difficulty in coping with the disability, as they make it that much harder for residents to develop a sense of self esteem. Moreover, the resident's very limited opportunities to form relationships outside the group home, and to do meaningful, satisfying work and get paid an adult wage for doing it, deprives the residents of the basis for self esteem - "the ability to work and to love."

Presently DMH Central is engaged in an anti-stigma campaign for people with long-term mental illness. Though this is a positive start and should be expanded, there is simply a

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limited amount of change in community atitude that can be
accomplished from the central office of a state agency. A
program similar to Alcoholics Anonymous, which promotes
positive self identification and group solidarity, could be
started for and by long-term mentally ill people in many
communties around the state.

The case manager, by meeting with the client in non-service
settings can also promote positive self identification and
community integration. Meeting in these settings give the
client opportunities to assume roles other than service
recipient and to engage in normal community activities, such as
shopping, on an individual basis. As much as possible, the
client should determine the location, the activities and the
pace of these outings in the community. These meetings should
be considered as opportunities for the case manager to get to
know and appreciate the client apart from any service setting
or therapeutic objective.

As we have seen from section 1.4 <u>Group Process</u>, client choice
is essential to making group process work. Clients who don´t
want to be in a group home can easily disrupt the entire group.

To succeed in the community at all, clients must have some
investment in where they live. Unlike the hospital where the
environment is controlled by the staff, in the community

residence the resident must participate to some degree in shaping his/her own environment and in controlling his/her own behavior. Particularly in the group home, where one resident's actions has repercusions for all the other residents and staff, clients must decide if and how much they want to stay in the residence.

Mental health professionals who don't work in group homes often don't understand the importance of client choice. They tend to see it as the group home staff not wanting to work with the really difficult clients. As one social worker commented:

> "Therapists have to understand when a client can't be handled in a residential setting. There will be times when they want us to take a client who just isn't suitable - because they're assaultive or have dangerous smoking habits. We work on getting staff and therapists to respect each others opinions. Therapists can get aggravated with community residence staff."

The therapist in the private residence also noted this tendency for hosipital staff to think that group home staff were being finicky in deciding which clients could make it in their residence. In the case of private residences at least, this misunderstanding between hospital and community staff was not accounted for by the pressure to decrease the inpatient census. Rather there seems to be a more fundamental misunderstanding between hospital and community residence staff about the need for client choice.

Group process calls for a high degree of cooperation from residents and/or orchestration from staff. Keeping the group home running means balancing both group and individual needs. Too much emphasis on one means neglect of the other. Staff in rejecting certain clients as inappropriate are often striving to maintain that balance between group and individual need and keep the groups resources from being stretched too far.

The long term relationship between the client and the case manger could provide many opportunities for the case manager to give the client individual attention, and thus lessen the client's dependence on the residential staff to fufill all his/her social needs. Case managers could also work on helping clients become comfortable pursuing community activities and relationships independent of the case manager. Like group home staff, the case manager must work at leaving open the possibility that the client may over a long period of time be able to act independently, while at the same time allowing the client to depend on him/her for direction, assistance and intervention as needed in the present.

Overall, given the advantages and disadvantages of group home life, it is clear that group homes have a place in a plan for providing housing for people with long-term mental illness, albeit a much more circumscribed and clearly defined place than they presently occupy in Massachusett's approach to housing the

long-term mentally ill population. SROs, foster care, supported family care, sattelite apartments and supervised apartments also have roles to play in a housing plan for long-term mentally ill people. Optimal use of each of these types of housing situtations by people with long-term mental illness needs to be researched, and the kind of staffing and support services which make each kind of dwelling habitable need to be delineated.

A well designed and implemented case management system could improve the functioning of all different types of community residences by providing the client with additional social and emotional support, and by assisting residential staff in obtaining services and social welfare benefits for the client, as well as keeping them informed of the client's current status in their other service programs.

In Chapter Two, I examined the group homes relationship to the state mental health system. The way this relationship has developed and the contradictions in it, has implications not only for how to improve the functioning of group homes, but also of other community residences and for the system of community-based care in general.

As we saw in section 2.1 <u>State Hospitals</u>, long-term mentally ill people in the community have a need for crisis intervention

and respite services, a need for some place with a high level
of external controls and a low level of demand, a place they
can go to "when life becomes unbearable".

Group homes cannot fufill this need and at the same time act as
normalizing, home-like environment for the client. In lieu of
other alternatives, many group home residents use the state
hospital to fufill their need for respite and crisis relief.
Years of experience with state hospitalization has taught many
clients to rely on the state hospital to serve this purpose.
Other group home residents who have never entered the state
hospital, and who have access to private psychiatric hospitals
through the use of Medicaid, find the same sense of refuge and
relief in those settings without being subjected to the
indignities of state hospital life.

DMH is moving to cap state hospital admissions without
developing community alternatives to state hospitalization. At
the same time, DMH intends to provide quality inpatient care to
a small, but as yet to be defined group of acute and chronic
patients.

Case management can be used by DMH to take a more active role
in identifying, developing, and channeling clients toward
community based crisis intervention and respite services. The
state hospitals traditional role of "provider of last resort"

needs to be unlearned by both the community and the clients.
Only by promoting readily identifiable and accessible
alternatives to state hospitalization will it be possible for
the state hospital to redefine its role.

One model for crisis care is to use a community crisis
intervention team. This team would be listed in the phone book
and known to local police. The team would make contact with
the client in crisis wherever they lived in the community and
would try to stabilize him/her in that setting. If the client
needed further assistance, the team would have access to a 14
bed unit located in the community where clients could stay for
up to 3 days. If the client was still not stabilized, they
could then be referred to a respite care house in the
community.(20)

Respite care houses could be developed for mental health
clients as has been done for MR clients in Massachusetts. In
these low demand, high control settings clients could stay for
up to six months while recuperating from a psychiatric crisis.
Case managers could coordinate the use of both crisis
intervention teams and respite care houses, as well as
supplement these resources by helping long-term mentally ill
clients get access to beds in private psychiatric, community
and general hospitals in the Area.

One of the points of dispute between the state hospitals and the community residences has been the residence's unwillingness to take clients from the state hospital whom the vendor deemed inappropriate for their residence program. A solution to this dispute is for DMH to put out client specific RFPs for residential programs for clients who are chronic state hospital patients.

An Area Office official I spoke to had done a client residential needs assessment for all the clients from her Area who were long-term residents of the state hospital inpatient unit. (see Appendix 2) She identified a need for highly specialized community residence programs to serve the dual diagnosed: mentally ill/substance abusers, clients with organic brain syndrome who have symptoms of both mental illness and mental retardation, and medically ill/mentally ill elderly. Her data was coroborated by observations made by stafff, vendor administrators and other Area Office officials. Staff commented on the MH/MR clients who could not be adequately served in their program but had no place else to go. Several Area Office officials and vendor administrators noted the lack of programs to serve substance abusers and the frail, low functioning elderly.

It is clear from this data that there is a mismatch between the clients in the state hospital who need highly specialized

community residences and the type of community residences
currently available. It is also clear that the data on the
residential needs of the chronic state hospital population is
readily obtained. The work of the Area Office official in
counting the number of long-term state hospital patients in her
Area, and determining their residential needs could easily be
duplicated in each of DMH's 24 Areas.

DMH should make an accurate residential assessment of the
chronic state hospital patients. With the numbers in hand, a
more informed dialogue about how to meet the residential needs
of the most severely disturbed, long-term mentally ill patients
could begin. And the counterproductive pressure on community
residences, to "take state hospital patients first" when their
programs are not designed to handle the multiple disabilities
of many of the chronic state hospital patients, could end.

There is a fundamental contradiction between trying to run both
a community-based and institution-based system of long-term
mental health care at the same time. Community-based care is
predicated on managing a disability with the lowest level of
intervention possible given the client's condition. The
purpose of community-based care is to use services to maintain
the client in the community so as to give the client the
opportunity to form connections to that community - a room of
his/her own, a familiar bus route, a convenience store where

he/she always buys coffee. The principle of community care is that the longer the client stays in the community, and is able to find the supports and services he/she needs in the community, the more likely he/she is to be integrated into community life. Case management is of central importance because it makes a system of community-based care possible.

In contrast, institution-based care is predicated on a medical model of mental illness. The client is removed from the community for episodic treatment and returned to the community once they are well again. The recurrence and duration of "episodes" of psychiatric crisis for the long-term mentally ill person, however, inevitably means a disrupted and disconnected life if treatment consists of a series of removals to an institution and returns to the community. Exclusion from community life is virtually guaranteed by instituion-based treatment. State hospitals, such as they exist in Massachusetts today, represent the continued use of a system of institution-based care.

The transfer of care for long-term mentally ill clients from the state hospital to the community is incomplete. Clients are caught between two worlds: a deteriorating system of institution-based care, and a partially developed system of community-based care. It is not possible pursue the development of both systems at once. A decision must be made

between investment in state hospitals, and investment in the many different types of community mental health services necessary to make a case management system effective.

Some advocates for the long-term mentally ill equate state disinvestment in institution-based care with a repudiation of state responsibility for assuring that the needs of long-term mentally ill people are met. They worry about access, accoutability and quality in a community-based system that relies on private vendors to provide mental health services to long-term mentally ill people. Experience with vendors going out of business, or refusing to serve certain clients, or underserving clients, has made some advocates wary of an entirely community-based system. At least the state hospital provides a safety net for clients who vendors won´t or can´t serve. And a state run mental health system is more subject to advocate´s using political pressure to induce change and demand accountability.

Many of the concerns over access, accountability and quality in a privitized system of long-term mental health care could be addressed by a case management system. Case managers would be employed by DMH and thus would be responsible to DMH and to the public for insuring that "difficult" clients were served. By collecting data on patterns of service usage for individual clients, case management could introduce a higher level of

accountability by having to account for clients who drop out of the system, as well as for clients who use an extremely high proportion of services without becoming stabilized. Finally, because case managers would work closely with vendors and clients, they could provide more accurate, up to date information on the quality of services than could be gleaned from the data collected anually by DMH central.

As we have seen in section 2.2 <u>The Relationship between DMH and the Vendors</u>, DMH trys to regulate vendor quality and accountability through monitoring vendor bookeeping, housekeeping and record keeping. The purpose of these regulations is to keep vendors from going under financially, assure certain minimum health and safety standards, and insure that clients are receiving treatment for their disabilities and not just custodial care in a community setting.

Staff, vendor administrators, and Area Office officals contend, however, that DMH regulations do not achieve these purposes. Rather than insure vendor financial viability, the added bookeeping and record keeping necessary to meet state reporting requirements, shift vendor resources away from client care. Typically, vendor residential programs are marginally funded and staff are called on to do bookeeping and record keeping in addition to client care. There is also little money in vendor budgets for physical maintainence of the residence and direct

care staff are also called on to repair and clean the residence in preparation for yearly licensing inspections.

The low level of staffing, and the extent of direct care staff's responsibilities for clients insures that major clean up and repairs are done once every one or two years for the benefit of the licensing inspector. As one staff person commented, "It's like your mother-in-law coming to visit." Ironically, even when substandard health and safety conditions are uncovered by the licensing inspection, DMH often cannot close down the program for lack of other residential vendors to which they can turn.

DMH central should reassign the monitoring of vendors to case management. DMH central could then concentrate its efforts on working with vendors to expand their administrative capability, and to develop in conjunction with them realistic budget and record keeping guidelines. Minimum health and safety standards could be assured the local fire and health officials inspections which routinely take place anyway, and which duplicate many of the checks done in the DMH inspection. Case managers could then follow up and make sure that residences were cleaned and maintained on a regular basis. For its part, DMH could work to foster a public/private partnership with the vendors instead of the more adverserial relationship that currently exists between the department and the vendors.

The quality of residential services cannot be assessed by yearly inspections and accurate record keeping. The quality of a residential program is a function of the staff-client relationship and the program activities and treatment philosophy. In order to assess quality, its necessary to interact with the program staff and clients on a regular basis and to visit the program informally. All 3 Area Office officials that I spoke to seemed to have this kind of working knowledge of clients and programs. Making quality assessment a function of case management seems a realistic goal in light of the Area Office officials ability to discern which vendors are running high quality residences.

The ISP (section 2.3), which DMH uses to monitor vendor accountability for providing treatment, also does not fufill its intended purpose. Staff, vendor administrators and Area Office officals all agree that the ISP bears little relationship to the resident's progress, and that the procedure for writing and updating ISPs can be demeaning to the resident.

DMH has made the mistake of using a therapeutic tool as a monitoring device. Because the deficits of long-term mental illness are primarily emotional and social, acknowledging them can be painful for the resident. The public nature of the ISP process violates the resident's right to privacy in discussing his/her emotional life and personal history. In addition, ISPs

are counterproductive in that they decrease the resident´s
sense of control over his/her own life by allowing others to
set and monitor life goals for the resident. Finally, ISPs
lead to artificially high expectations of resident progress
given the long-term nature of the resident´s disability.

There are other indicators of resident progress which are less
intrusive and more accurate than the ISP. Community residence
tenure in and of itself is usually a marked improvement for
most long-term mentally ill clients. Decreased use of crisis
intervention and respite services over time is another
indicator. Staff that I spoke to in several different
residential programs gave examples of clients who´s use of
inpateint facilities had decreased over the course of several
years of being in the residence.

One vendor administrator put together a chart comparing client
state hospital use before and after placement in her residence.
(see Appendix 3) The decline in inpatient use for almost all
the clients listed is an indicator of both individual progress
and overall program quality. Other indicators of resident
progress include regular attendance at vocational workshops and
regular meetings with a therapist.

It is important to note that all these indicators are only
meaningful in the context of the individual clients personal

and psychiatric history. For a client who was hospitalized for 6 months out of every year, reducing inpatient use to 3 months out of every year is an impressive achievement. Keeping these indicators in the context of the individual client's life is another reason why monitoring quality and accountability for serving clients should be done at the case management level.

Throughout this conclusion I have discussed various strategies for using case management to improve services for long-term mentally ill people. I have not proposed a specific model of case management services because the design of a case management system should take into account bureaucratic, budgetary and political constraints that go well beyond the scope of this paper. Case management models using single case managers or case management teams, having a caseload of 20 to 120, including a range of professionals from psychiatrist to social worker or employing only case workers, and working in either rural or urban areas, have all been used successfully.(24)(25)(26) One of the most important criteria for the success of a case management system seems to be the commitment to reorganize the existing mental health service system to make case management the focal point for service development and delivery, and not just another layer in the mental health service bureaucracy.

The following qualities of an effective case management system

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are derived from existing models of case management and from

the discussion in this thesis of many of the problems facing

long-term mentally ill clients and service providers:

1) "Continuity of Caregiver" (27) - This formulation goes beyond continuity of care, which emphasizes the continuity of treatment approaches and treatment settings, to stress the importance of the caregiver-client relationship. Thus it takes into account the difficulty many long-term mentally ill people have in forming and maintaining relationships.

2) Flexibility of Services/Flexibility of Funding - The case manager cannot provide services on a flexible basis unless they also have the ability to move funds around. Fixed investment in facilities and programs impede this flexibility. The trade-off between fixed and flexible investment in services and programs must be recognized and addressed within the existing mental health service system if a case management system is to work. If the bulk of the mental health service system budget is invested in fixed programs and facilities, this leaves the case manager with little disgression as to how to tailor services to fit individual client need.

3) Follow Clients across Settings - One of the most valuable aspects of case management is the ability to follow client across setting. For the long-term mentally ill client who often can't speak for themselves, particularly when they are in crisis, the case manager can provide a coherent case history to other service providers and advocate for the client's best interests.

4) Collection of Data - The case manager is in a good position to collect qualitative and quantitative data on clients, services, and providers, and to communicate that data to the central office to provide a mental health service system overview. Citizens advisory groups and professional consulting groups should periodically provide and independent assessment of service system functioning.

5) Administrative Oversight - The case manager should make sure the client is receiving all income supplements, housing allowances, and other social welfare benefits to which the client is entitled. The case manager should also work to ensure access for long-term mentally ill people to all generic community resources such as transportation and recreation.

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6) <u>Therapist/Administrator</u> - The viability of case
management services depends on the case managers ability to
balance these two roles. Training, adequate compensation,
time to get to know clients individually, and built-in
access to the various components of the mental health
service system would all the case manager in keeping the
roles in balance.

Case management is not a cure-all for many of the dilemmas

described in this thesis, or for the many other problems that

plague the public mental health system. In particular, there

are three main dilemmas which should be recognized as obstacles

to effective case management.

The strength of the case management model - the ability to both

work with clients and to work with the system - is also its

weakness as well. The case manager is a candidate for double

burnout: political burnout from fighting battles with various

service bureaucracies both within and outside the mental health

system, and client burnout from working very closely with

clients who have numerous needs, few resources, and who may

only achieve small gains in functioning over a very long period

of time. It may be too much to expect that one person, or even

a team of people could successfully integrate these two roles.

Secondly, case managers are severely limited in what they can

do for clients by the shortage of all types of low income

housing. "Normal" low income housing units are fast

disappearing across the country. In Massachusetts, public housing is oversubscribed with waiting lists of 5 to 10 years a common occurence; and "specialized" mental health housing is coming on-line at a very slow rate. Residential services are not just one service among many that long-term mentally ill people need. Community residences provide the base around which to organize the rest of the client's service needs. Without a permanent residence, the benefit to the client of any other services is mitigated.

Finally, the limit-setting dilemma will not be solved by case mangement. The limit setting dilemma revolves around the question of how far a client should be directed toward rehabilitation, and how far toward acceptance of their disability. The unpredictability of the course of long-term mental illness makes this question difficult to answer. Much more research needs to be done on what long-term mentally ill people want to achieve in life for themselves, as opposed to what society or the mental health service system believes they could or should achieve. This thesis has been a start in that direction.

Footnotes

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Appendix 1

<u>Interviews done for Thesis</u>

13 Staff

 9 Residents

 5 Vendor Administrators

 3 DMH Area Office Officials

 3 Family Members

 2 Executive Office of Human Services Officials

 2 Division of Capital Planning and Operations Officials

 2 Department of Mental Health, Central Office Officals

 2 Researchers on Community Residences

 1 Therapist in a Private Community Residence

Total: 42 Interviews

Residential Program	Fy '85 need	Fy '86 need	Fy '87 need
Supported Apartment	3	5	5
Community Residence	3	9	6
MH/Substance Abuse Residence	11	9	5
Behavior Shaping Residence Staff Secure	9	8	6
Psychiatric Nursing Residence Staff Secure	7	12	6
On Grounds Transitional Residence	4	5	5
Geriatric Unit	5	2	4
MR/MI Unit	7	6	5
Forensic Unit	3	5	4
Other	1 Rehab. Facility	1 MR Residence	1 Wheelchair Access Communities
Acute Unit	—	—	7
TOTAL	53	62	54

Appendix 2

(page 154)

(page 155) Privacy Code # — Appendix 3	Date of First Psychiatric Hospitalization	Date of Admission to Program	# of Psych. Hospitalization PRIOR to Entering Program (# of Admissions)	# of Psych. Hospitalization WHILE IN Program (# of Admissions)	TOTAL # OF DAYS of Psych. Hospitalization PRIOR to Entering Program	TOTAL # OF DAYS of Psych. Hospitalization WHILE IN Program	Date of Exit from Program (or S.T.-Still There)	Time in Program from Date Entered to 12/1/? Expressed in Terms of Year: ie., 6 months=.5 year, 1 month=.083 year, 2 months=.16 year, etc	# of Years from First Hospital Admission to Date Entered Program	AVERAGE # of Hospital ADMISSIONS per year PRIOR Program	AVERAGE # of Hospital ADMISSIONS per year WHILE IN Program	AVERAGE # of Days per year Spent in Hospital from First Admission to Entering Program	AVERAGE # of Days per year in Hospital WHILE IN Program
Mr.1 (B)	8/3/47	3/29/85	7	0	6022	0	S.T.	2.66	37.75	.19	0	159.52	0
Mr.2 (B)	2/51	9/1/87	7	0	574	0	S.T.	.25	36.66	.19	0	15.66	0
Ms.3 (R)	7/20/51	4/28/86	13	0	781	0	2/7/87	.83	34.83	.37	0	22.42	0
Mr.4 (B)	11/11/54	9/3/85	3	0	9576	0	S.T.	2.25	30.916	.10	0	309.74	0
Ms.5 (R)	1960	4/29/85	11	6	223	65	S.T.	2.583	25.416	.43	2.32	8.77	25.16
Mr.6 (B)	9/15/61	7/1/85	13	1	1053	21	8/22/86	1.25	23.83	.55	.8	44.19	16.8
Mr.7 (R)	5/27/69	4/29/85	9	0	2051	0	2/27/87	1.916	16	.56	0	128.19	0
Mr.8 (B)	11/23/69	8/1/86	42	2	3996	49	S.T.	1.33	16.75	2.51	1.50	238.57	36.84
Ms.9 (R)	12/5/69	4/29/85	6	1	1890	16	S.T.	2.583	15.5	.39	.39	121.94	6.19
Ms.10 (R)	1974	4/29/85	1	0	10	0	4/25/86	1.083	11.416	.09	0	.88	0
Ms.11 (R)	1975	4/29/85	13	0	636	0	S.T.	2.583	10.416	1.25	0	61.06	0
Mr.12 (B)	7/31/75	8/21/85	7	0	187	0	8/30/87	2.083	10.16	.69	0	18.41	0
Mr.13 (B&R)	9/75	10/31/86	5	2	1005	33	S.T.	1.083	16.25	.31	1.85	61.85	30.47
Ms.14 (R)	1976	10/24/86	8	3	215	41	S.T.	1.083	10.916	.73	2.77	19.70	37.86
Mr.15 (B&R)	8/76	3/4/85	12	0	318	0	S.T.	2.75	9.66	1.24	0	32.92	0
Mr.16 (B)	12/77	8/15/85	3	7	117	161	8/30/87	2	7.83	.38	3.5	14.94	80.5
Mr.17 (B)	5/29/87	3/2/87	11	1	659	7	S.T.	.75	8.83	1.25	1.33	74.63	9.33
Mr.18 (B)	7/10/79	3/1/86	2	0	82	0	8/1/86	.5	6.75	.30	0	12.15	0
Mr.19 (B)	6/25/80	7/1/85	7	3	203	36	S.T.	2.416	6.083	1.15	1.24	33.37	14.90
Mr.20 (B)	12/5/80	3/2/87	12	0	806	0	S.T.	.75	6.25	1.92	0	128.96	0
Mr.21 (B)	1981	4/29/85	2	3	112	29	11/30/85	.66	4.416	.45	4.55	25.36	43.94
Ms.22 (R)	2/12/81	4/29/85	8	2	102	39	8/28/86	1.416	4.33	1.85	1.41	23.56	27.54
Mr.23 (B)	7/4/83	12/5/85	8	2	122	26	1/16/86	.083	2.416	3.31	24.10	50.50	313.25
Mr.24 (B)	2/14/85	7/1/85	1	2	22	76	2/28/86	.75	.416	2.40	2.67	52.88	101.33
Mr.25 (B)	4/18/85	3/3/86	6	1	124	4	S.T.	1.75	.916	6.55	.57	135.37	2.29
Mr.26 (B)	0	9/13/87	0	0	0	0	11/20/87	.16	0	0	0	0	0
* * * A V E R A G E S * * *			8.35	1.38	1187.92	23.19	* * *	1.44	13.64	1.12	1.88	69.06	28.71