CASE STUDIES OF ASSISTED LIVING IN NEW YORK: HOW WELL DOES THE RHETORIC MATCH THE REALITIES?

JULY, 2001

The Coalition of Institutionalized Aged and Disabled, Nursing Home Community Coalition of New York State And The HealthCare Management Program, School of Business and Management – Temple University

Part of *The Assisted Living Project,* a three-year project funded by the Fan Fox and Leslie R. Samuels Foundation

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We gratefully acknowledge the help of the Empire State Home and Assisted Living Association and the New York Association of Homes and Services for the Aging for writing letters to their members urging them to welcome and meet with project staff on the on-site visits.

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EXECUTIVE SUMMARY

Introduction

Description of Project The Assisted Living Project, a three year effort supported by the Fan Fox and Leslie R. Samuels Foundation, provides an objective, systematic description of a rapid, major transformation of care for the frail elderly whose long term implications for New York residents remain unclear. The project included a statewide survey of assisted living[1] and an environmental assessment[2]. The third part of the project, a policy white paper, is being released at the same time as these case studies. For the purposes of the project, assisted living facilities were defined as those facilities that either provide or arrange for assisted living services such as personal care services or helps with activities of daily living such as bathing, dressing and toileting. This definition includes licensed adult homes, enriched housing, and assisted living programs and unlicensed facilities that met our definition. In the statewide survey, 470 assisted living facilities in New York State participated in a 163-item telephone survey that achieved an 84 percent response rate. It provides an accurate overview of current operations and dilemmas faced by facilities. The environmental assessment supplies the historical and organizational context propelling the assisted living transformation of care in New York. The policy white paper condenses the conclusions of the above research efforts, including the In Depth Case Studies, into an action plan.

In Depth Case Studies The In Depth Case Studies explore the nuances and unanticipated complexities of efforts to operationalize the promises of assisted living as a home, a place to age-in place and an environment that allows for the autonomy and flexibility not possible in more "institutional" settings. It also looks at some of the issues related to the financing of assisted living for those using public funding as well as those paying privately and issues related to the staffing of these facilities. For the In Depth Case Studies, our research team conducted ten on-site visits to facilities representative of the diversity of assisted living arrangements in New York State. This included six-predominately public and four private pay only facilities and included unlicensed facilities, licensed adult homes, enriched housing programs and assisted living programs. Five of the facilities were for profit and five were not-for-

[1] Nursing Home Community Coalition of New York State, The Health Care Management Program, School of Business and Management – Temple University and the Coalition of Institutionalized Aged and Disabled. A Summary of Assisted Living in New York State: A Summary of Findings, April, 2000.

2 D. Smith, The Assisted Living Rebellion: Class, Community and The Transformation of Care. An Environmental Assessment for New York City. The Assisted Living Project, Nursing Home Community Coalition of New York State, The Health Care Management Program, School of Business and Management – Temple University and the Coalition of Institutionalized Aged and Disabled. It will be published in book form next year.

profit, and five facilities were large (99 beds and higher) and five were small. Geographically the sites were also varied: seven were in urban locations, three were in suburban locations, and one was in an exurban location. The site visits were two days in length and involved interviews with key supervisors and managers, focus groups with residents and staff, a review of documentation of policies and a tour of the physical layout, both inside and out. Several telephone interviews with family members were also conducted. All the facilities we visited were extraordinarily responsive and cooperative during the entire course of our project work.

Questionnaires and a protocol for observing the facilities environment were developed by the research team and used during all the site visits to collect information. [3]

The Case Studies are organized by those areas that represent the fundamental promises and challenges of the assisted living industry: (1) aging-in place; (2) autonomy; (3) risk taking; (4) staffing; (5) finances; and (6) regulation and licensure.

RESIDENTS: THE TENSION BETWEEN THEIR WISHES AND THE REALITIES OF ASSISTED LIVING

Aging-in Place: Growing Dependent in Place

Most individuals would prefer to remain in the facility they live in even if their health deteriorates (i.e., "age-in place") and most of the evidence supporting the effects of transfer trauma and the importance of social support networks argues for the wisdom of such preferences. Consumers are often led incorrectly to believe that assisted living facilities promise a living arrangement where they can age-in place, and implicit in this promise, avoid nursing home placement no matter how sick they become. However, aging-in place in the organized care giving settings we visited remains, with few exceptions, more rhetoric than reality. One facility clearly wants to be a place where residents can age-in, and is developing programs to meet the developing needs of its residents. But many others, either by design or practice, are operating as one level of care within a continuum of care.

We found several key factors that challenge the ability to age-in place. First, and foremost, there has to be the financial resources available, either by private means or government support, to pay for increasing care needs. Almost as important is the issue of whether residents can age-in safely - can the facility care for a more dependent resident. Other factors we found influencing a resident's ability to age-in were the willingness of the facility to retain residents as they decline (is it concerned about looking like a nursing home?); the acceptance and quality of life of other residents; state regulations; the physical design of the setting; the mission of the

3 For copies of these protocols, please contact the Nursing Home Community Coalition of New York State (212-385-0355).

facility; how the facility is organized and its staffing; and the influence of family members.

In most of the facilities we visited, staff spoke about the increasing dependence of the resident population. Residents were aging-in and some staff said their residents were similar to a nursing home population. Most of the facilities did not plan for this change; they had to deal with it as it arose. We found that most of the nursing staff we questioned knew how to assess and treat common issues that often lead to nursing home placement: incontinence, accidents and cognitive impairment. Thus, we hope that staff were unlikely to suggest nursing home placement for residents with such symptoms before trying to discover whether some symptoms were reversible and/or whether they could be treated in the assisted living facility.

Issues related to cognitive impairment seemed to cause most of the concerns from the alert residents' point of view. They complained of having to deal with residents with dementia. Facility staff also spoke about having to deal with these complaints. A few decided to separate dementia residents from alert residents by developing dementia floors or wings, but this had an added issue of some alert residents fearing being sent to the dementia floor. Residents also spoke of not wanting to be with "old, sick" people and not wanting to have a facility that looks like a nursing home.

Autonomy

Individuals in our society place a high value on their freedom to make their own choices and not be dependent or controlled by others. This does not diminish with age or infirmity. Besides the value autonomy has for us in its own right, research has shown that for the elderly, there is an important relationship between autonomy, self esteem, well-being and health. The importance and value of autonomy has not been lost on providers of assisted living. Assisted living facilities, in contrast to the institutional nature and public perception of nursing homes, promise residents housing and services that foster choice and independence in care and lifestyle.

In order to explore the personal autonomy of residents living in assisted living facilities, we asked staff to describe for us the choices residents have regarding food, activities, doctors and home care agencies and the ways they minimize the effects of institutionalization and organized group living. For example, we looked to see how residents' privacy was protected. We also inquired about facilities' resident council programs, a classic vehicle for promoting resident decision-making power. We asked residents whether they had control over the decision to move to the facility they live in, what kinds of choices they have in the facility and how living in the facility was different from living independently.

The views of staff and residents regarding autonomy seemed to be at variance with each other. Most facilities seem to offer a range of choices for their residents, and most staff seemed to believe that if residents have, for example, a few choices at

meal times and choices of different staff developed activities, a residents' autonomy and independence was being promoted. Some residents we met with seem to feel that autonomy means more than just being offered alternatives decided in advance by the facility. Focus groups with residents at each site indicated that the ability to be autonomous can be elusive in reality. They have had to adapt their lifestyle, some, depending on the facility, more than others, to the circumstances of group living, to the circumstances of their functional abilities and disabilities, and to the particular constraints of particular facilities. In one facility, however, the facility has clearly adapted itself to its residents, and seeing that, we wonder how subtlety less flexible other places may be. These other places may indeed embody the type of community and norm residents want, but how much are individual expressions of selfhood allowed to flourish there? It is difficult to assess, but several residents did talk about not being able to stay if you were "uncooperative" or a behavior problem. Some residents spoke of their feelings of loss of control in certain aspects of their lives with acceptance and resignation. Others raised issues in more assertive fashion, and as complaints. In all these cases, questions were raised as to how responsive facilities are or can be to these issues. Resident councils should offer a vehicle for educating staff about these things and a forum for taking concrete steps to address them, but most councils seemed ineffective in this function and did not function as a method for promoting resident decision-making power.

The question of a person's autonomy and decision-making power in assisted living is first tested in the initial decision to move to the facility. While some residents we met made the decisions themselves, or in consultation with other family members, other residents had the decision made for them. Typically this happens in a time of crisis by a family member or, in some cases a hospital discharge planner or protective services agency worker. Staff in some facilities believe the large majority of residents do not move to assisted living willingly, and many facilities market to the family and not to the potential residents. Given that, it seems, facilities must work not only to maintain but also to help restore the autonomy that has been lost.

Having your own "space", either an apartment or a private room, was a key element in the ability of an individual to maintain independence and autonomy. We found that residents' sense of control was enhanced when they had their own apartment or room, and staff seemed to share in that perception. Staff access to resident apartments or rooms was an issue in a few facilities however. Other privacy issues such as privacy of records and information or staff discussing residents within earshot of others were also concerns in some facilities.

Most facilities offered choices in food and activities, although in a few facilities the choices were limited or lacking. All facilities allowed residents a choice of doctors, but many of the facilities have a preference for the doctor used most predominately by residents because of the greater efficiency in coordination and administration. Fewer facilities offer a choice in home care agency. This may be because there are few home care agencies to choose from. In one facility you do not choose the agency

but have a choice of the individual caring for you. A few residents complained about lack of choice regarding schedules (mealtimes; having to get up for breakfast; bathing). The physical limitations of a facility or its location (insufficient activity space, unsafe neighborhood, broken pavement, inaccessible to the community or public transportation) were also evident in a few facilities, causing residents to lead more circumscribed lives. Several facilities provide transportation for trips and errands but residents of only one facility seemed satisfied with its availability to go where they wanted to go when they wanted to go. Even here, residents missed having their own cars and the freedom that brings. Pets are allowed in some facilities if provisions are made for caring for the pet if the owner is sick or dies (others cannot allow because of regulations). Residents rarely participated in the running of the facility such as choosing decorations, or hiring staff. Resident councils were places for residents to complain, not to be involved in shaping facility policy.

One of the issues that concerned us was the possibility of the institutionalization (i.e., learned helplessness and passivity) of some of the residents we observed. Institutionalization is a danger in any organized setting of dependent persons, and the promotion of autonomy, decision-making and choice is a critically important intervention to address it. There are several factors that seem to contribute to this complex problem. In facilities where we observed this issue, some residents were not involved in the decision to move to the facility. Not being involved in the important initial decision to live in such assisted living arrangements might lead to less successful adaptation. These facilities were caring for a more dependent population where residents were aging-in to a greater extent than other facilities. And they were also facilities that were not providing or could not provide the kinds of choices other facilities could.

Risk Taking

Risk and risk management are important concepts in assisted living. Differentiating themselves from nursing homes, assisted living facilities are marketed as places where you are able to maintain control over your life, including the ability to make decisions and take actions that may involve risk. Nursing homes, on the other hand, are typically viewed as limiting risky behaviors, decisions and actions because of their institutional nature (which constrains individuality) and because of concerns with liability.

The ability of residents to take risks or do something staff believed "unsafe" was a difficult concept to evaluate. Assisted living facilities and its staff are balancing a resident's right to take risks with the facility's understanding of its responsibility to ensure the resident's safety as well as liability issues. The factors that influenced the degree of residents' risk-taking abilities included: (1) the attitude and beliefs of management and line staff (did they feel comfortable when residents took risks?), (2) the feelings of the residents themselves (did they fear doing something staff believed unsafe?), (3) the design and type of the facility (enriched housing seemed to *allow*

and *require* the most risk taking), (4) the presence or absence of 24 hour supervision (an absence of staff means there will automatically be more risk taking), (5) regulatory interpretation (do regulations allow or prohibit risk taking?), and (6) the presence and attitude of family (how do they feel about their relative's risk taking?).

Risk contracts, formal vehicles between consumers and assisted living facilities, are frequently mentioned as vehicles for protecting both consumer self-determination and facility liability. The Assisted Living Federation of America (ALFA) has developed materials to promote risk contracts as a way to handle this issue. We found no regular, formal use of risk contracts in any of the ten facilities we visited. Instead, most of the facilities we visited use an informal policy when residents wished to do things staff felt were unsafe. A few facilities seemed to have a more established procedure than others, such as the use of staff meetings and documenting informed consent.

Most of the professional and direct care staff we spoke to practiced "persuasion." The language that was used most to describe this practice was trying to convince or talk a resident out of some perceived risky behavior or offering alternatives to the behavior they considered risky. Some staff spoke of educating and counseling residents. It should be noted here that among some proponents of the assisted living industry, the practice of persuasion and the offering of alternatives is already a violation of the idea of control over one's life. We did not find that sentiment in any of the facilities we visited, except possibly for facility # 8 (see below). In fact, in some facilities, we got the strong sense that the threat of calling family was used as a way of persuading residents out of risky behavior. If a resident still wanted to take the risk, some facilities seemed more risk adverse than others depending on some of the issues listed above. In one facility some staff will actually bar residents from taking a risk.

A number of facilities will call families to stop residents from taking risks. However, it seemed in some instances, facilities, quite appropriately, call families to inform them about a perceived risky situation and to involve them in some cooperative effort to resolve the situation.

We did hear an example of how staff in one facility does try to encourage residents to take risks in the form of going out on trips. Some of the residents in this facility are not likely to go out. They are mostly homebound and will refuse to go on outings because they are afraid of falling, or that it is too far away, or that a bathroom will be inaccessible to them. Still the facility makes an effort. They were successful in getting them out to a kindergarten graduation one block away with children that are part of the inter-generational project they are involved in.

In discussing risk-taking, we are talking about people who are capable of making an informed decision about whether they want to take the risk or not. There are residents who are clearly not capable of making an informed decision about risks because of

their cognitive impairment. As in nursing homes, however, there may be residents where the situation is not so black and white: some residents may be able to make certain informed decisions, but not others, or they may be able to make decisions at certain times and not at other times. Assisted living staff should be knowledgeable and may have to be more flexible in handling these situations.

Of all the sites we visited, the enriched housing models seem to allow and require more risk taking by residents because of its physical and program design: independent apartments and lack of 24 hour supervision. Residents were on their own after the workday was over. However, we found differences even among the enriched housing sites we visited.

CAREGIVERS: A STRUGGLE TO KEEP THE PROMISE OF ASSISTED LIVING

Staffing

Staffing issues are of concern in all health care settings. The assisted living environment had similar issues. The large majority of staff seemed to be dedicated and loved working with residents in this setting. They spoke of experiences they had with their own family member needing care that encouraged them to look for such work. Many said a difficult aspect of the job was watching residents who have become like family become more dependent. Some staff talked about the difficulty dealing with residents' psycho-social issues: residents who cannot accept the facilities as their homes, who are resistant to care, or have a hard time dealing with the fact that they need help and cannot do for themselves.

We did find some major issues related to staffing problems. Low wages and limited benefits were problems for many. In two facilities we found a practice of cutting work hours depending on the facility census; if the census was down, a full-time worker could become a part-time worker. In one facility, a man was unable to support his family when his full-time hours were cut; he had to look for another job. In some contradiction, some aides spoke about the difficulties keeping good staff, while some managers said they had no problem with turnover or getting good staff. However, our other findings pointed to the fact that there were problems getting and keeping staff - many of the workers we spoke with were new to the job, and one facility told us they regularly recruit and interview. At one facility, workers complained about the lack of teamwork of some of their colleagues, the fact that they are sometimes used as universal workers (do other jobs as well, such as maintenance and activities) and the lack of respect and recognition. At one facility, there was friction between workers and supervisors over the open-ended nature of the job and the demands of residents. We found examples of good practices as well. One facility has cross-trained its staff to do a number of things and we found a high level of

teamwork. At another facility, it was apparent that staff were respected and held in high regard by the administrative staff.

Finances:
Creation of a "Two-Tiered" System of Assisted Living Care

Much of the recent explosion in assisted living has been in facilities that are catering to a "high-end" private market, elders or their children who are in the upper middle income bracket of $50,000 to $100,000, people who can afford, at least for a time, $5,000 or $6,000 a month. For various reasons - children who need help with their parents, isolation and loneliness, a house too big to take care of anymore, and for all, the very strong desire to stay out of a nursing home - the private pay only assisted living market has grown to meet consumer demand.

But what of low- and middle income elders of $50,000 and under – those who use public funding or can afford to pay privately less than half of what the private pay only charge? They want and need a similar package of services for some of the same reasons. They, however, can choose only from those places that are willing to accept low rates of public funding or offer lower charges: some adult homes, enriched housing programs and licensed Assisted Living Programs or "ALPs" that serve an indigent frail elderly population. Some of these places cannot compete with those places that accept only private pay. They have fewer amenities. Thus, we have seen a "two-tiered" system of assisted living developing -- one for the upper middle class and one for the poor and middle and lower middle class.

While a number of facilities have developed creative ways of dealing with the low rates of public funding, these low rates are exacerbating this issue for the others and is threatening the very existence of such programs. Except for the ALP, which receives a daily rate of 50 percent of what a nursing home would be paid by Medicaid on top of the Supplemental Security Income (SSI) rate (about $27 a day), the cost of a person's care often exceeds the public assistance the resident receives. We found that this situation has already resulted in the reduction of the number of SSI recipients one facility feels it can afford to care for and some of these places are going out of business.

Four of the ten facilities we visited were exclusively private pay and the prices far exceed the public rates. (One facility will on a rare occasion admit a SSI/Medicaid recipient, with the family making up the difference). They tend to look prettier than the facilities accepting public money and all were running at full or close to full occupancy.

Private pay prices are high. At some licensed private pay facilities this rate covers everything. At others, the rate covers only the residence part and other services are

extra. Three of the facilities offer such a menu of services. For example, at one facility medication administration is $8 per day. At another facility, 3.25 hours of personal care services for a dementia resident is $65 per day; another offers 24 hour one-to-one care for $1,225 per week. At the fourth facility a narrower range of services and units are offered for a uniform price of $2,400 to $3,000 per month.

The high rate of residence and care is causing concern even among those that can afford the costs when they first enter. The practice of adding additional charges has led to some resentment. The administrator of one facility believes his payment structure is better than other facilities because he does not "nickel and dime" residents. He does not charge extra for every little thing. Residents we spoke to at one of the other private facilities did indeed resent the fact that everything was extra. One woman was upset to get a large bill when she needed help with dressing for a limited time and was charged a lot to go by van to a doctor.

Some of the private pay facilities are not interested in the financial resources an individual has. They consider themselves a hotel-like residence and when money runs out, the individual has to leave. Some of the facilities look for people who can afford the prices for 3 to 5 years or more. We found few places where residents had run out of money and were asked to leave. However, we did find evidence of residents spending down. At one of the facilities, individuals often are forced to go from a private room to a double occupancy room because they are running out of money. This has happened to most of the residents we spoke to during a focus group meeting, and while some talked about how reassuring it was to have a roommate, it was obvious the motivating factor was affordability. One resident was quite angry and defensive about the situation. At another facility, some residents who have spent down are transferred to a "sister" nursing home as Medicaid eligible nursing home residents.

This practice also adds to another problem. When an individual can no longer afford this "high market" facility, they often end up in a nursing home on Medicaid. Thus, more and more private pay money is being taken out of the nursing home system, making the nursing home system more and more a system funded by Medicaid.

Six of the ten facilities in our on-site sample were facilities that accepted public entitlements and served a largely indigent population. These facilities offer a different model of care than the private pay only facilities (a "second tier'). Furthermore, while a few are figuring out innovative ways to deal with the inadequacy of public funding, others are either absorbing large losses, restricting admittance to private pay only or are considering closing. We may soon find that we can no longer offer even this second tier option or we may find the quality of care suffering dramatically because of low public rates.

Four of the six facilities lose money, and one of these is closing down because of chronic low occupancy. All six facilities suffer from the low $27 per day rate they

receive for the care of their residents on SSI. The facility that is closing is a lovely homelike adult home that used to admit people on SSI and had a sliding scale. Now they admit only people who can pay privately at the full rate, which is about $2,000 (this includes room and services). The administrator told us the facility had never broken even, and wouldn't even if at full occupancy. A good endowment that contributes half the budget helped keep it afloat. The other facilities have learned to use different strategies to survive. One facility, a combined enriched housing/ALP program runs a deficit of about $175,000 annually, which is subsidized by the local United Way. While SSI pays $27 a day, according to the administrator, the daily costs per resident are $43. The administrator's argument to the United Way each year is that the facility is saving the taxpayer the greater cost of nursing home placement by delaying such placement. Will this support continue? A small enriched housing program run by a large social services agency is, according to program staff, a major money loser ($50,000 last year). Most of the residents are on SSI, and the cost for the program is $47 per day, per resident. Thus, they say they are losing $20 a day per resident. The strong financial position of the agency, sustained by larger programs that bring in surplus revenue, supports this program without the need for cutting operating costs. However, there are no plans to expand the program and the agency is in the midst of plans to build a large private pay assisted living facility. Another enriched housing program is losing $40,000 a year when it is at full occupancy. It was losing even more money until it changed its food service, which has resulted in major complaints from residents. This program is skilled in using Medicaid home care to provide additional help for residents who need it. And at one combined adult home/ALP, the ALP program keeps the facility afloat, covering the losses sustained by the adult home. Here the ALP actually allows the facility to be able to function at a lower private pay occupancy level than it needed to before opening the ALP program, resulting in a net addition of SSI recipients they are able to serve. The ALP program was developed to allow licensed adult homes and enriched housing to care for nursing home eligible people and receive Medicaid funding for the health care component of services. This program is limited, however, in New York State.

Regulation:
The Argument For and Against Licensure and Regulation

Licensed facilities must meet minimum standards related to admission, discharge, staffing and services offered. The New York State Department of Health monitors compliance with these standards. Facilities that are not licensed do not have to comply with minimum standards and are not inspected by the State. However, any home care agency supplying services to residents in unlicensed facilities must be licensed, comply with home care rules and are monitored by the State.

Unlike licensed facilities (which may need to apply to the State for waivers), unlicensed facilities can admit and retain any individual they want to. This may be positive in that it may allow residents, who might otherwise be transferred to a

nursing home, to age-in. However, there are potential negative outcomes: unlicensed facilities may admit or retain people it cannot safely care for. In one facility that had dipped below full occupancy, nursing staff felt pressure from the marketing staff to change their established admission criteria and admit a medically unstable individual who the nurse believed they could not care for. The nurse refused to admit this individual, but it's an instructive story regarding how the pressure to maintain full census may lead an unlicensed facility to accept residents it cannot care for. The continued building of "high market" assisted living facilities may lead to a glut on the market. This may lead more and more to pressure from competition and may lead to unlicensed facilities accepting residents no matter what their needs are and no matter what their ability is to care for them.

Governor Pataki proposed a number of recommendations around regulations and licensure of assisted living facilities in New York State in 1999.[4] One of these is to allow facilities to choose to be licensed or "registered" rather than require all facilities to be licensed. Registration would require certain disclosure requirements, but would not involve care regulations or care oversight by the State. Another recommendation would change present regulations to allow licensed facilities to be able to admit almost anyone they want and to retain any one they believe they can care for.

Some facilities would choose registration over licensure for themselves because they believe they give quality care and don't need oversight (however, others may need it); others felt it was dangerous not to require every facility to be licensed; others looked at licensure issues as it was related to profit and competition: one would choose licensure because it feels there is more money in it; another did not want unlicensed facilities to be licensed because it would bring more competition; another believed that competition demanded uniformity (all should be licensed); and one related licensure to mission; it did not want to choose licensure because of a philosophy of aging-in. One facility also spoke of the problems of meeting the "land use" and certificate of need rules and zoning requirements as reasons for not choosing licensure.

A few of the licensed facilities seemed to be more upset with the way compliance with the regulations is monitored than with the idea of regulations or licensure; two mentioned that the regulations require them to do things they are not reimbursed for.

Some of the administrators commented on the Governor's recommendation that licensed facilities be able to admit almost anyone they want and to retain any one they believe they can care for; some in more than one way. Of the three who commented, two were concerned about the costs, one was concerned about the problem of caring for people who would be unsafe and one spoke about the problem of keeping a "social model."

[4] Governor Pataki, The Assisted Living Reform Act, Program Bill No. 68, May, 1999.

Discussion

1. Ensuring *Safe* Aging-In Place

Evidence of financial pressure and lack of organization and planning led us to question whether residents were aging-in safely in several of the facilities we visited. Increased competition to keep beds filled and the likelihood of continued staffing problems fueled by the worker recruitment and retention crisis in the health care field in general will continue to challenge safe aging-in. The places we visited, however homelike they seemed, still felt and acted like health care institutions. As such, we are led to consider

whether all facilities should be licensed and follow uniform minimum standards of disclosure, admission, discharge, assessment, care planning and quality assurance.

2. Advancing the Promise of Aging-in, Autonomy and Risk Taking

Because of current regulations limiting types of residents that licensed facilities can admit or retain, we found that residents did not seem to be able to age-in place in licensed facilities to the degree they could in unlicensed facilities. This makes assisted living one part of a continuum of care rather than a place where people can stay and get whatever care they need. This raises the issue of whether existing regulations should be reviewed with the goal of encouraging safe aging-in place to a greater extent than is now occurring. Safe aging-in place might be promoted with the relaxation of certain regulations and the establishment of certain other protections. We also found room for expanding resident autonomy, control and risk taking in the assisted living facilities we visited. Therefore, regulations might also be reviewed to enhance and support informed risk-taking, choice and control, recognizing that assisted living facilities seemed institutional in nature and that significant numbers of residents did not decide to move there on their own.

3. Achieving the Real Promise of Assisted Living Through Ownership and Governance

Promoting greater aging-in place and enhancing resident choice and control within the current organization and structure of assisted living facilities is only one step in the evolution of the true vision of a non-institutional assisted living setting. Ownership and resident governance truly provides the assisted living resident with the promises made by assisted living for autonomy and one's own independent lifestyle. Of the assisted living facilities we visited, we found the enriched housing model coming closest to these goals, providing private, non institutional apartment living more equally to rich and poor alike. Beyond the representative assisted living models we visited, the naturally occurring retirement community or NORC may offer the elderly real "ownership" since the residents are tenants with leases and cannot be thrown out if they get sick. In addition, resident councils should be evaluated for their ability to influence the running of the facility. We may indeed be able to achieve assisted living's real promise by exploring the ways in which NORCs can be emulated and resident councils can be vehicles for true participation in governance.

4. The Contradiction of Assisted Living: Aging-In Place and Quality of Life
During our visits, we found residents suffering a diminished quality of life because of the aging-in place of their neighbors, to such a degree that many felt they were living in a nursing home, exactly what they were trying to avoid. Assisted living facilities are grappling with a major but largely unspoken challenge: balancing real aging-in place for its residents while preserving the quality of life these same residents are seeking. Assisted living facilities may be doing themselves and their residents a disservice by telling consumers what they want to hear, but not facing the tension of its goals. Assisted living facilities may need to address this contradiction in their goals more creatively and forthrightly, finding ways to reduce the impact of aging-in place on other residents by preparation, planning and design.

5. Paying the Price
Safe, dignified aging-in place is an illusive privilege of the few. Only those who can afford to pay and who are fortunate enough to find themselves in facilities designed, budgeted and staffed to accommodate aging-in place will have this choice. Those who exhaust their private resources face limited choices lacking in basic privacy and amenities that often seem more like incarcerated punishment than care. Public payments to facilities for those that lack private resources make aging-in place hazardous. The victims of this increasingly income segregated system of financing are those receiving care as indigents, the institutions that provide it and society as a whole that bears the greater cost of a two tiered system of care. More careful assessment of a system that relegates the indigent to the most costly and often most inhumane arrangements for care may well demonstrate its folly and spur basic financing reform.

6. Taking Care of the Caregivers
As in nursing homes, direct care providers are the most important contributors to the safety and quality of life of residents in assisted living facilities. One of the great strengths of assisted living is the richness of the bonds that are often formed between caregivers and residents. It is an important source of satisfaction among staff. During our on-site visits we heard vivid evidence of this from managers, direct care staff and residents. We found most staff to be dedicated and caring, enjoyed working with elders, and felt it was not just a job. However, the weakness of assisted living facilities, acknowledged by many, is the low pay, lack of benefits and difficult work conditions that of necessity often makes the employment of direct care staff transient. Given the well-documented problems of staff shortages and turnover in the fields of health and long term care, it is not surprising that similar problems exist in assisted living. It is critical that the issues related to the recruitment and retention of direct care workers in assisted living are addressed before the problem becomes overwhelming.

THE CASE STUDIES

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Aging-In Place: Growing More Dependent In Place

Facility 1: Private pay, for profit, suburban unlicensed facility

Aging-in Place as a Mission: A Facility Where You Can Age-in Place, But Only If You Have the Resources

It is clear that aging-in place is a key aspect of this facility's mission. It wants to be a resident's final home. According to the marketing director, their unlicensed status is due to the fact that licensed facilities in New York cannot admit or retain persons in wheelchairs, in need of two-person transfers or who are cognitively impaired. They would prefer to be licensed but wish to care for sicker residents, and will, if these residents have the resources to pay for more help as care needs increase. For it is also clear that the facility allows people to age-in only if they have the resources. This facility accepts only private funds, and if a resident runs out of money, they are discharged. This happened to two residents who had been friends for 40 years and were sent to a nursing home with early and middle dementia and incontinence. Some staff told us they would have been fine here if not for the lack of funds.

The administrator estimates that about 85 percent of the present resident population will be able to remain until death.

According to staff, the population has changed since the facility opened. "Every one of the residents has deteriorated and aged in place." The aides we spoke to felt that many of the residents were similar to nursing home residents.

Can Residents Age-in Safely?

The facility believes that it can safely take care of anyone who does not need day to day medical and nursing monitoring or is medically unstable, e.g., those on ventilators, tubes, IV's, on diets that need special monitoring such as renal diets, or persons who are dangerous to themselves or others. The nurse seemed extremely knowledgeable about assessing the causes of such issues as incontinence, falls, walking and transfer issues and cognitive impairment, and how to go about dealing with the issues. At a time of low occupancy, the facility considered admitting a resident with a Foley catheter. The facility did decide not to admit this person. However, this does raise a question about whether facilities would admit residents they really couldn't care for if under financial pressure.

The facility clearly wants to push the "aging-in envelope" and actively looks for ways to allow people to age-in by developing programs to treat common issues that often lead to nursing home placement. They have an incontinence program that includes bowel and bladder training for the cognitively intact, and indeed, 70 to 75 percent of the residents are incontinent. If residents become cognitively impaired they move to the facility's special dementia unit. They recently instituted a two-person transfer for residents who need it. Residents can receive physical therapy for issues related to falls or walking.

Attitudes of Residents

For the most part, the residents we spoke to understand that someone will be discharged if they need skilled nursing care, run out of money or become "uncooperative". One resident said she was originally told she could stay here until she died, but found that was not quite true. Residents were tolerant of other residents' physical declines, except "we do not like it that it looks like a nursing home . . . residents sleeping and falling out of their chairs." Several said they didn't expect the degree of physical and mental disabilities of residents, and talked about the negative effect it had on their quality of life. However, they were far less tolerant of the cognitively impaired than the physically impaired, and they did not want to be with these residents. "Its better for them but not for us". It's a major complaint at resident council meetings. Perhaps cognitive decline is more difficult to confront because some expressed the fear that they would be sent to the dementia unit. Families also share in this because staff reported families' difficulty in accepting this type of decline.

Facility 2: Private pay, for profit, urban adult home

Adapting to Aging-in Place: A Facility That is Responding to the Changing Needs of Residents with Resources within State Regulations.

This licensed adult home is instructive as one that did not originally set out with a mission to allow residents to age-in place, but adapted, with some struggle, to the aging-in of its population by expanding services. As the nurse of this facility explained: "When I first started working here twenty years ago, maybe there were fifteen residents you needed to assist with their medications. The population could come and go. They had their own cars and some of them worked. It was like a hotel. It was a very non-medical care setting. Now we tend to be more on the lower end of the nursing home. It is a combination of aging-in and more recently changes in what hospitals and nursing homes will take. Now about 25 percent have a degree of dementia and 25 percent are incontinent with the majority of these needing assistance."

This facility caters to a private pay population and like facility # 1, the ability to age-in place is limited by the ability to pay for enough care to meet growing needs. However, because this facility is licensed, aging-in is also limited by New York State regulations. These regulations set out rules about whom one can admit and whom one can retain. They cannot admit persons in wheelchairs (unless they ask for and receive a waiver) or who need two person assists. Like facility # 1, this facility cannot admit people needing tubes and individuals who are a danger to themselves or others.

Can Residents Age-In Safely?

The nurse case manager was very knowledgeable about assessing and addressing incontinence, falls, walking and transfer issues and cognitive impairment.

Attitudes of Residents

The facility has plans to open up an Alzheimer's unit. These plans are, for the most part, internally motivated, both in terms of the needs of the residents and the complaints of other residents. The residents we spoke to did indeed say they found the cognitively impaired residents a problem, and the facility recognizes it impinges on their quality of life. The administrator told us "the residents with Alzheimer's are very difficult. They interfere with the games, they talk, and some are very depressing to be around. Some residents have bad manners. It affects the quality of life here." Being responsive to, communicating with and seeking resident input seems to be part of the facility's efforts to succeed: the administrator again told us "we thought we'd have the same problem with walkers. The way I approached the resident council was to say, "Thank God I don't need a walker. If I needed a walker, would you be willing to let me stay?" I explained the planned changes in policies and asked for their feedback. It was a matter of presentation. If I had simply sent out a memo on stationary we would have had a lot of complaints." Besides struggling to sell aging-in

to its present population, the facility also has to find a balance for marketing itself to prospective residents: "Other residents will not be willing to come if they see too much of it (aging-in)."

There were other examples of quality of life concerns in relation to aging-in. On the night shifts, staff makes two-hour checks on the residents receiving cluster care. We were told that most of those receiving cluster care are in private rooms. However for those who are not, their roommates sometimes object to these disruptions.

Facility 3: Private pay, for profit, urban unlicensed facility

Residents Can Age-In Place, But only If They Have Enough Resources

The issues of cost and the problem of aging-in vs. quality of care are also apparent and replayed at an unlicensed facility we visited. The promise, as told to us by the administrator that "this is your apartment and you can live here for the rest of your life" is honored for those that can pay for all the additional services. However, other staff told us that if a resident cannot participate in activities or is in a wheelchair, they are inappropriate for this facility. Some do receive round the clock personal care by attendants. An outside home care agency is under contract to give personal care to about 40 percent of the residents who live here which includes the large majority of residents in the facility's dementia unit. They had a problem with one resident who had no family. He was in a shared room and could not afford a private room. He became incontinent, refused care and wouldn't take baths. He was sent to a nursing home.

Can Residents Age-In Safely?

We had questions about this facility's ability to ensure that residents are safely aging-in. An assessment of a person's care needs is made only after someone has moved here. Once a resident is in the facility, there are apparently somewhat erratic weekly meetings between the facility and home care agency staff about residents' care needs, but nothing that seems close to any real case management, leading us to question how well different staff are communicating about residents, particularly about those residents who are not clients of the home care agency. However, the nurse did seem to know how to assess and deal with issues related to incontinence, falls, walking and transfer issues and cognitive impairment. Some staff questioned whether there was sufficient staff to care for the residents needing care, 2 aides for approximately 40 residents on their non-dementia floors.

The experience of the adult daughter of an Alzheimer's resident who fell and hit his head may highlight this issue. According to the daughter (because of the desire of the daughter for confidentiality, we were unable to speak to the administrator about this), he seemed to have had an accident and was not helped for 12 - 14 hours. She also discovered that he lost weight even though she had informed the facility he needed assistance in eating. She called and was finally told that he had lost weight and she

should bring in Ensure for him to eat. If that did not work, he would be evaluated physiologically. This woman faces a dilemma. She has the resources to obtain whatever care her father needs and does not want a nursing home because of the poor care he received in one prior to moving to this facility. She likes the facility and yet it is not clear whether the facility can care for him.

As already mentioned, the large majority of the residents on the Alzheimer's unit are clients of the home care agency. One is not, even though staff believes she needs to be. We were told that the family is in denial and cannot afford the added expense. Currently the recreation staff handles her needs, such as showering, because aides work only for the home care clients. When asked about this, the administrator said that she knows that the staff does more than it should, but she also does not want to discharge a resident who has been here from the beginning.

The facility sometimes involves family in arranging care. They have recently had a problem with 3 residents who wander. As a stopgap solution, they have sent these 3 residents to the Alzheimer's unit during the day. They are thinking of telling the family that they must hire a 12 hour companion or aide on a one-to-one basis.

Attitudes of Residents

A number of residents we spoke to told us they specifically chose the facility because they wanted to be around more life and liveliness and not around so many old, sick people. Not surprisingly, the residents are not happy with the aging-in that is taking place. As one observed, "This is like a nursing home - people lined up at the door - urine - one of my friends tried to sit down in a chair and it was wet." Another resident told us, "We don't want to turn the mirror around and look at ourselves." This last comment succinctly summarized and underlined most residents' complaints: that dementia residents come to facility-wide entertainment programs and some of these residents are not housed on the dementia unit. It seems that in part, the question of aging-in vs. quality of life is a question of mainstreaming vs. separate levels of care. And as with facility # 2, aging-in place requires both the ability to provide the additional services needed and the expectation and acknowledgement of the process by other residents. This facility, as others, has done little to market the facility as such, which is obviously a far harder sell.

Facility 4: Private pay, not-for profit, urban enriched housing in a hospital integrated delivery system

A Facility's Mission to Be One Part of a Continuum of Care

Aging-in is not part of the philosophy of one urban enriched housing facility, which is part of a campus that includes a nursing home, hospital, independent apartments and adult day care. A connected building contains the independent housing units and the enriched housing program and currently one third out of the total units are enriched. With the exception of the migration of residents from the independent

living apartments, the enriched housing part of this development caters to a fairly narrow range of needs, with a conscious effort to focus on hotel or hospitality as the core mission. There is little ability for residents in the enriched housing to become frailer, less mobile, more cognitively impaired, or with increasing self-management of incontinence issues. The campus-like setting seems to provide a "continuum of care". Moving on this continuum, however, requires relocation that may, in terms of geographic proximity be only marginally preferable to placement in any nursing home or hospital in the region.

The restraints on aging-in place appear to be driven by the model and assumptions used in creating the independent and enriched units in the first place (e.g. that it would fit into and not directly compete with other parts of the integrated delivery system.) The pricing and, as a consequence, staffing were driven by those assumptions which in turn greatly limit the diversity of needs that can be accommodated. The facility is not interested in gaining waivers to keep residents whose needs exceed the existing level of care and would not change their policies even if the need to obtain waivers was removed.

Can Residents Age-in Safely?

The facility carefully screens residents for admission and there are daily staff reports designed to identify any concerns or general decline in a resident's functional or mental ability. Families can help out and hire private duty aides when a resident gets sicker or loses functional capacity but this is generally viewed as a transition arrangement pending more appropriate placement. It is not designed as a safe environment for dementia patients that wander, since residents may come and go as they wish.

Even with the careful screening and monitoring taking place, there appeared to be issues over appropriateness of residents and expectations in care between the nursing director and the manager. The nurse feels she is excluded from decisions about admission and discharge and felt about five of the residents should not be here.

Attitudes of Residents

The enriched unit was developed several years ago and was subject to a lot of initial complaints and discomfort on the part of those in the independent living units who found the frailty of these new residents a turn off. However, as more of the neighbors have gravitated to this wing, complaints have given way to visits, shared activities and a recognition of the advantage it provides to independent living residents in not uprooting themselves again from the familiarity and network of friends when they themselves become more frail.

Facility 5: Public pay, not-for profit, suburban adult home

Aging-in for the Poor and Middle Class

A not-for-profit adult home is representative of a seemingly by-gone non-institutional senior living model which cannot survive. In the past the facility had 50 percent private pay and 50 percent public funding. While their census still includes some residents who pay privately, some who pay on a sliding scale and several who are on SSI, they no longer admit residents who cannot pay privately, because of a low census. However, no one is asked to leave if they run out of money.

Even though they are now half filled, they retain the same staff they would have if they were full and they do not increase charges as someone needs more care. Thus, the cost of keeping a resident becomes prohibitive when staff has to provide more care at the expense of other residents. One widowed woman exemplifies the resident who exceeded the facility's ability to care for her: a stroke victim who could not walk well and had a speech impairment. She was placed in a nursing home because staff could not keep up with her needs. Other residents have stayed in the facility longer because they could pay for someone to provide morning and evening care.

Can Residents Age-In Safely?

Because they are only half full, they are taking older, frailer folks with more care needs. The staff are caring and dedicated and will go far beyond what can be reasonably expected. Because of that the facility can keep residents longer. This dedication and good will is recognized and supported by management who are protective of the staff as well as the residents in regards to the impact aging-in has on the facility. They do not worry if it gets too expensive, but only on how it will affect the entire facility community. As with several other facilities we visited, the nurse described extremely well the need to assess the causes of incontinence, falls, walking and transfer issues and cognitive impairment, and how to go about dealing with these issues.

Residents have to be ambulatory (can have walker, but no wheelchairs) and be able to feed themselves. The design of the facility and its surrounding grounds prohibits residents with mobility issues from staying here. They seemed concerned about the ability of staff to care for individuals with even more care issues. They will keep incontinent residents " only if staff can deal with it." A lot of diapers are used. A number of residents are cognitively impaired, but they stay away from people with other behavioral issues (e.g., acts out, yells, curses, threatens, is disheveled) because of its affect on the needs and wishes of other residents. They do not admit or retain people who need on-going nursing, are in wheelchairs or are not self-directing, because it is not only prohibited by state regulation but because it is important that

staff morale be maintained. The administrator told us, "one resident can drag staff down, and they get crabby." Most people leave because of death or need a higher level of care. There has always been a question of "what happens when I get sicker". People have been allowed to die in the facility who did not want to go to hospital.

Facility 6: Public pay, not-for-profit, suburban enriched housing

Lack of planning for Aging-in Creates Problems

Aging-in Place Safely

This enriched housing program provides a homelike residential setting to a frail elderly SSI population that is neither age nor income segregated. Its residents have lived there for many years and the program has existed with little focused administrative attention, almost invisible within a larger residential housing program. However, the aging-in and consequent growing needs of its current residents have in the last several years focused new attention to the program. It provides three meals a day, with personal care and some nursing services. The on site staff include two direct care aides (64 hours total) that provide light housekeeping, laundry, meals and "assist" with medications. It was clearly set up for a much healthier population. As its population got sicker, it began to utilize other services such as adult day care. In addition to the staff required under the enriched housing regulations, additional personal care aides are hired with Medicaid dollars to assist with the needs of individual residents from the sponsoring agency's home health agency.

As in all enriched housing programs, the staff leaves at night, and there are limits to the type of care needs this program can accommodate. It is clear that this program has not been able to meet the growing needs of their residents. Up until recently it had little nurse oversight, even though many of its residents were on multiple medications. It is now struggling with trying to find placement or an adequate accommodation for two residents who are cognitively impaired and incontinent. It is dealing with residents and relatives who do not want to leave.

It is also a very tight living arrangement, which makes it difficult to accommodate individual personal care staff without impinging on the other residents. The more cognitively intact residents complain.

Facility 7: Public pay, not-for-profit, urban enriched housing

Continuum of Care for the Poor and Middle Class

This urban enriched housing program is affiliated with a nursing home. The program contains studio and one-bedroom apartments housed within a building with other apartments. The program clearly sees itself on the continuum between independent living and nursing home care and view what they do as trying to figure out the best placement for people, with nursing home placement sometimes being the better

placement. The program benefits from being able to draw upon a lot of professional services from the nursing home that is used for assessment and intensive case management services. The residents have access to the facilities and services of the nursing home including an adult day care center and physical and occupational therapies.

The program does not take private pay residents, providing assisted living services to poor and middle class clients. They are able to do this by offering their residents subsidized apartments and a mix of services provided by their own home care agency and the Medicaid Home Care Program. Unlike the other facilities discussed so far, aging-in place here is not limited by resources and cost, but, in the view of the program's manager, by the ability to coordinate services. The program uses the nursing home's own licensed home care agency to employ 3 aides to provide the classic array of enriched housing services: housekeeping, shopping, escorting, preparing and serving food. Aides do not provide help with activities of daily living (ADL's), although they do provide some assistance with bathing. If residents need more than the services offered by the program (6 hours a week of aide time, one meal a day), the program applies for home care under Medicaid, which they seem adept at arranging for. Over half of the residents use the Medicaid Home Care Program and almost half use the nursing home's day center. Sometimes family is asked to supply care-giving if needed to keep them in the program.

Can Residents Age-in Safely?

They look for highly functional people who need congregate housing, but they are taking less functional people because they need to fill beds.

The program does seem very, very careful about keeping anyone who needs more help then they feel they can provide. However, they look at each case separately, in some instances obviously having to weigh the options or lack of options a person has. They kept one resident in the program (with 24 hour home care) after the family insisted she remain and not be sent to a nursing home. This woman was hallucinating, leaving the gas on, eating the cat food, wandering the halls at night and accusing the staff of stealing. Even though the State felt she was at risk, few nursing homes would accept her (because of low scores). As the program's manager told us, "sometimes people's needs exceed the program's ability to care for them but there is no place to put them."

Attitudes of Residents

The residents we met with did not seem to know to what extent they could age-in and drew conclusions from experiences of others residents. They had varying opinions -- some felt that if you got too sick, you were sent to the nursing home; others disagreed. They told us they wouldn't want to live with others who were cognitively impaired or a hazard to the community.

Facility 8: Public pay, not-for-profit, urban enriched housing ALP

One Facility - Different Levels of Care

Can Residents Age-in Safely?

This urban enriched housing program also has a licensed Assisted Living Program (ALP). Residents range from independent living, to enriched housing to the ALP within the units operated by the sponsoring agency. This facility can care for incontinent residents, and with a waiver, people in wheelchairs and people who can transfer with one assist. One obese lady who needed a two person transfer had to be transferred. The separate apartment units and the freedom of residents to come and go as they please also limit the nature of the population that can effectively age-in place in this setting. It is not an appropriate site for Alzheimer's patients because of the separate apartment units all residents have. It is ideal for medically complex, cognitively intact self-ambulating residents who have a desire to maintain their independence. The aging-in of this independent and autonomous population is very tough on the staff though, which seems to contrast with the balance facility #5 strives to strike between the needs of the residents and the needs of the staff (albeit with a more institutionalized population of residents – see above).

Attitudes of Residents

The initiation of the ALP program created tension with the original enriched housing residents, who are fiercely independent and had strong objections to the increased supervision and staffing and the encroachment of these new neighbors on their turf. There were battles over the use of the community room. In spite of this history, there do seem to be real benefits to having a mix of residents of varying functional ability under the same roof in terms of maintaining the independence of frailer elders. The director of the ALP told us that the frailer residents in the ALP benefit from living with the well elderly in the enriched housing because the mix lends itself to people feeling more independent. People are motivated to get out more than they probably would. And in contrast to the conflicts that arose when the ALP program was first opened, the residents look out for one another now.

Facility 9: Public pay, for profit, urban adult home ALP

One Facility - Different Levels of Care

This licensed adult home, like facility #8, also has an ALP program. The facility provides a good illustration of the definite advantages to having two levels of care within the same facility, both in regard to continuity of care and the reduction of transfer trauma. If an adult home resident here needs more care, they can become an ALP resident and receive the care without moving from their room. The administrator told us that 80 percent of their ALP residents come from the adult home. The benefits are even greater when you consider that seven to eight residents a year need more care on a short-term basis. They become ALP residents temporarily,

and when they are better, become adult home residents once more without having to go through the disruptions of a move.

In addition, the ALP deals with the issue of the needed resources required for aging-in. The administrator, as did other administrators of ALP's, told us that the Medicaid reimbursement adequately funds the facility for the needed care.

Attitudes of Residents

However, there are concerns with moving people out of the ALP and back to the adult home, if a resident improves. The administrator told us that residents will sometimes object because they like their present aide.

Having two levels of care is not without its problems in regard to other residents' quality of life, as we have seen in the other facilities we visited. Here we were told that roommates of adult home residents who become ALP residents complain about too many staff coming into the rooms. This was dealt with by having many of the cluster care residents in private rooms or explaining to staff to be more sensitive by knocking on doors.

Limits to Aging-in

If a resident needs too much care for the ALP, they will be transferred to a nursing home, where, we were told, many die within a few months. Even during her short time in the facility (almost 1 year) the nurse in the ALP has seen the population change - 3 to 6 have been sent to nursing homes during her tenure. According to staff, residents are transferred because they are taking too much staff time and need too much care.

Facility 10: Public pay, for profit, exurban adult home for psychiatric and elderly residents

Aging-in of the Mentally Ill

This adult home was unique among the facilities we visited because it houses a diverse population of mentally ill and elderly residents. As with other adult homes that care for the mentally ill, a younger deinstitutionalized mentally ill population has been aging-in to this facility. Some of the residents in this facility have outlasted the facility's owners, living at the facility almost all of its twenty-six year life. The median age is now somewhere between 65 and 70. The oldest resident is 95. The facility is applying for a limited licensed home health agency so that they can bill Medicaid directly for additional services that are needed. As with other adult homes included in our case studies, this will allow them to hire additional personal care staff, probably provide more continuity and integration of care and certainly improve the operating margin.

The Governor's Assisted Living proposal as presented in 1999 would spin off those facilities with 40 percent or more mentally disabled and label them as Residences for Adults rather than assisted living. The concern here is the disenfranchisement of the mentally ill to age-in place. Why should those with a mental health diagnosis not be allowed to age-in place, since in the process of aging, as the medical and functional problems grow, the mental health problems can recede in importance?

The State fears that these facilities are in danger of being labeled institutions for the mentally disabled (IMD's) which cannot receive Medicaid dollars. According to the State, making all adult homes assisted living facilities, endangers the State's federal Medicaid funding.

Autonomy

Facility 1: Private pay, for profit, suburban unlicensed facility

The Decision to Move to the Facility

The marketing director told us that residents come here because families do not want to take care of them at home, and estimated that 90 percent of the people who live here did not want to be here. One couple moved here because their children urged them to be near them, yet they don't see their family as frequently as they would like. "This is a big step - we gave up our independence; we live near our children, but they are busy." Of the five residents we spoke to in a focus group held here, 4 said they chose to live in an assisted living facility on their own, although of those 4, the families of 2 residents actually selected the place.

Having Your Own Space

This handsome unlicensed facility seems to have everything money can buy in regard to maintaining an independent lifestyle. It offers residents apartments that range from studios to suites. The apartments have kitchenettes with refrigerators. Residents can supply their own microwaves.

Choices/Control

Even so, a major issue seems to be how much autonomy individual residents are given here. The facility maintains a great deal of contact with family members. This is laudable if it means the facility is trying to keep interested family involved and not trying to respond only to families' requirements. We were not sure if in this facility staff was not bypassing the residents to deal primarily with family members. This was certainly the case in the area of resident risk-taking. Families were called and told competent residents were taking risks against staff wishes. And it is clear that the children are the targets of marketing, usually a caregiving daughter in her fifties.

According to the staff, residents have lots of choices: when to get up, food choices, a choice of two different seatings at meals, and activities. Their plans are

individualized. All rooms can be locked from the inside, although the staff has master keys. Residents can have pets but they must be able to care for it. There is a van for scheduled outings and for doctors' visits two days a week. The activity director told us "They pay the bills", and by extension, they therefore have control.

Residents painted a slightly different picture, however. One resident said, "I can't do what I want. We have to live by the rules - meals at specific times, even if there are 2 seatings. We can't go out and do what we want." Other residents also discussed the problem of getting out into the community. "Transportation is a big problem; we were told there was a van and there is one but it cannot be used whenever we want. Residents want to go to more places." Another resident told us "I can't go to the hardware store to get something."

Residents also complained that the activities are not what they are interested in. For example, one resident mentioned her desire for more intellectual activities. The activity director is young and new to the job and did not seem very knowledgeable in how to find out what residents want. She asks them. When asked if she has ever reviewed the "profiles" filled out by all residents and families about their preferences in activities, she said no.

Resident Governance

Similar to other facilities we visited, the resident council here is not really a council. It's a time when residents can complain but they have no real say in any policies. For example, even though residents would like to change the menus and have raised this at council meetings, they were told that the menus come from corporate headquarters and can't be changed. The activity director, who helps staff the council, does not see it as a vehicle for maintaining or enhancing self-determination. They have some say to the extent that their care plan is individualized, but as a group, they have no influence. The residents meet every month with the Director, the Activities Director and the Food coordinator. One resident told us that when she complained about the food staff didn't listen to her, but when she had her son complain, there were changes. This seems to support the sense that the family is the primary customer here.

Facility 2: Private pay, for profit, urban adult home

The Decision to move to the Facility

Most of the residents we spoke to lived in the neighborhood and came here looking for companionship after the death of a spouse or because of the need to be cared for after a medical crisis. One resident whose daughter had moved away didn't want to cook anymore or be alone. She shopped for a facility herself and tried out several for a few days before selecting this facility. Another resident who came for a two-week trial period ten years ago told us that she did not want to depend on her children or neighbors and was looking for companionship. The five other residents in the group

we met with had other people decide for them - typically a daughter, though in one case a doctor made the choice for one woman.

Having Your Own Space
This licensed adult home offers its residents semi-private and private rooms with private baths, but no kitchen and cooking facilities (which is prohibited by State regulation). For those in semi-private rooms, they try to match up roommates and we were told that sometimes there are problems. They give everyone a "2 week tryout." However, any one can leave with a 7 day notice.

Choices/Control
Apparently in recognition of the importance of providing more independence and choice regarding food, the rooms in a new wing of the facility have microwaves and the option of having a refrigerator. The facility is working on providing a communal kitchen where residents can cook or entertain. The staff told us that residents have choice in a variety of areas including food and activities. The activity director told us, "We try to get them to make decisions by offering choices in activities", though it was not clear whether residents' have decision-making power in determining what activities are offered. One woman in the resident focus group said she felt there were no activities that were really what she wanted. We were told they have a choice of foods at mealtime and residents can choose to eat in their room at times. They can also choose their own doctors and home care agencies. However, one resident complained about the lack of control he has scheduling important aspects of his day. He told us he did not like the cluster care he receives because he could not take a shower when he wanted. Aides told us that if a resident does not want to take a shower, they come back at another time, which is good practice. However, during the night, aides check on their residents by going into the room. Sometimes a resident objects to being woken up to have a diaper changed. They tell the resident, however, that it is part of their job and they have to do it.

Privacy
The facility believes it helps protect residents' privacy by listing residents' dietary needs on the dining room tables only if residents agree. This is an example of a facility giving some control to residents.

Resident Governance
The Resident Council meets every month. The staff told us that residents raise issues - and have "a voice". They make complaints and requests and are very vocal.

Facility 3: Private pay, for profit, urban unlicensed facility

The Decision to Move to the Facility
The nurse told us that a difficult problem for the care-giver is that the resident never accepts this as their home -- they always want to leave. This may be related to the fact that some residents here were not involved in the decision to move here. Of the

residents we spoke to during a focus group meeting, 4 chose to live here for themselves, and family made the decision for 3 residents.

Having Your Own Space
The residents live in nice sized private rooms with private baths. There is no separate kitchen area, but each room does have a microwave and refrigerator. Residents have control of the temperature in their room.

Choices/Control
There seem to be many different choices at this facility according to the residents who participated in the focus group we held here. For example, there is an impressive activities program that offers residents many choices. Residents go on many trips and have access to transportation for errands, shopping and events. The facility has its own bus that is used for outings everyday to churches; stores; banks; racetrack; Atlantic City; concerts in the park, etc. They can choose their own doctors. They can get up when they want. They choose their food from menus. And according to the activity director, they have input into the food and activities. The facility is responsive to their requests and complaints. "When they complained that the soup was like dishwater, the chef made it thicker. He listens to them." The activity director changes activities depending on what works and what doesn't. And when we asked residents how living here was different from living on your own, some residents spoke positively about the companionship they had found ("You're never alone with four walls") and the release from (at least some) responsibility, as other residents elsewhere has said: "You don't have to shop, stand in line and deal with all the frustrations."

Privacy/Institutionalization
Yet other residents feel limited. One resident discussed the lack of privacy: "I had more freedom at home - people barge in on me; staff has a key to my room." And another resident told us, "Everybody is involved in your life here - told to go here and there - everything is organized - like cattle - not human." The activities director told us they miss their old neighborhoods and the freedom of their own cars.

Resident Governance
According to staff, when the residents ran the resident council themselves, it suffered from internal turmoil. The activity director now runs the council and its meetings, and she spoke to us about the difficulties of organizing strong and demanding individuals into an effective group and how stressful it is for residents. "Although residents raise issues and make suggestions, mostly it has been a shouting match. There is a domino effect when one starts yelling, the others start. If it can be kept low key, with only one staff person there, the residents are calmer and listen and are willing to share." It may be that residents have traded "ownership" of the council in order to work more cooperatively as a group under the direction of the activity director. Its effectiveness and organization still seems to be a question, however,

because although we were told there is a six member resident committee and they act to solicit concerns from other residents, other residents we spoke to had never heard of this committee. The residents we spoke to felt that the council was ineffective because they do a lot of talking but get no results.

Facility 4.: Private pay, not-for-profit, urban enriched housing in a hospital integrated delivery system

The Decision to Move to the Facility

For all but one of the seven residents we spoke to, the adult children made the choice about moving here. One resident moved in initially to the independent living section. "It has space and quiet, removed from the hubbub of the City, but there is transportation." While the children on the whole did the shopping for the facility, "you put the final OK on it. We had the final decision." The activity director sees a major part of her role as helping residents adjust and combating the loss of self-esteem residents' experience when they move here. She tries to keep them busy so they do not become depressed. She runs socials, reminiscence and other support groups, involves them in community help projects and takes them on trips to their old neighborhood. There was an expectation and an acknowledgement that it was different than living in ones' own home. One resident said, "You have to fit in, when you can't you're out on the street. I am in a group and I have to comply with the rules, but I can choose what activities I participate in or not."

Yet, the facility more than lived up to expectations and hopes in meeting their most important needs. "All I wanted was someone to say, I care for you. This place is home for me. I am treated as an individual person...my greatest need is for people to be kind and respect me. No arguing. I cried all the way here, but I haven't cried since. You come to a different plateau and you have to start over."

Having Your Own Space

The residents live in their own apartments. However there is a tight design in terms of floor space in the apartments and common areas. The administrator told us that the physical layout of the facility does create constraints. The activity director told us that "We don't have a central kitchen that they could use for cooking projects and we need a large enclosed room for some activities." The lack of a common kitchen for resident use was a big gap in her program because she could involve folks on a one to one basis. We found this design constraint, in different manifestations, in several other facilities we visited, where there are no private bathrooms, limited community space, or broken sidewalks that limit access to the outside.

Privacy

Staff told us that because this is a social model, it is easier to forget about the need for confidentiality. They said that the staff has to be constantly reminded about confidentiality. Out of genuine concern, residents ask questions and staff have to be

careful to avoid talking about the medical problems of residents with other residents. The activity director told us that sometimes she has to play dumb.

Resident Governance
The resident council meets once a month. Like many of the councils in the other facilities we visited, no real decisions are made. The activity director told us that residents seem reluctant to voice criticisms at this public forum. There are no officers. The residents have not been given a lot of input even though it appears it would be worthwhile - there are chairs in the dining room and other furniture that no one likes to sit on because they are uncomfortable.

Minimizing Institutionalization
The residents we spoke to during our focus group meeting here talked about how this facility differs from living independently. There is no place for people to stay that visit. There are three food choices and the facility will always make a sandwich if you don't want any of these. "They make stew not in the way I use to make it. There is too much food and the meals seem too close together." One resident said: "I am a do-it-your-selfer and I miss that." Another resident told us: " I gave up my car, it is a loss." This resident compared the regimentation he found here to his time in the army. "You have to discipline yourself."

Facility 5: Public pay, not-for-profit, suburban adult home

The Decision to Move to the Facility
A few residents we met with at this facility did not choose to come here. One resident was placed here by her ex-employer and has lived here for 10 years. She visited the facility before she moved. Another was dizzy one day and her landlady took her to the hospital (which she didn't believe she needed). The hospital discharge planner placed her here from the hospital. One woman lived in an unsafe neighborhood and was mugged. She believes she had no alternative. She did not visit the facility and her nephew selected it for her. Two of the residents came when the adult home sponsored by the organization this facility has merged with closed down. Both of them had health issues and could not live alone.

Institutionalization
One of the more striking things at this facility was that several of the residents here seemed to be suffering from the effects of institutionalization: passivity and learned helplessness. The staff recognizes the fact that residents are becoming institutionalized and are trying to work on a solution. The administrator told us that the residents "have gotten lazy and some have become helpless." The facility nurse told us that the residents "are physically and psychologically fragile and are regressing in their behaviors. Because many have abdicated responsibility for themselves by simply being here, they are vulnerable to depression and fear. They need that mood lifted." The facility tries to motivate residents to do more for themselves. Staff are trained to encourage residents to dress and shower themselves.

Staff is struggling with the issue of how to help residents become less passive and less dependent. The activity director told us that some staff disagree with the right residents have to refuse to participate in activities. Some staff feel residents should be forced to go to activities to combat the problem.

Having Your Own Space

In this licensed adult home residents do not live in apartments, but in private rooms. However, there is only one room that has a private bath. The individual units are distinct - there is no standard furniture and residents are allowed their own personal furniture and can arrange it as they wish. There are no separate kitchens, as they are not allowed by regulation. While not offering the personal autonomy of separate apartments with bathrooms and kitchens, (this is an adult home, not an enriched housing program) what the single rooms lack is partly made up for in the multitude and quality of the community spaces that include a living room, two enclosed porches, an open air porch, a library and an activity room.

Choices/Control

In other aspects of their life residents of this facility seem to enjoy less freedom and choice than others. Some residents gave examples of areas of their life they have lost control over. A few did not like the schedules telling them when they have to eat. They can't sleep as late as they want because they would miss breakfast. The administrator admitted they do not have a lot of choices, such as in food or meal schedules.

Residents have a choice of shower times, but only when the part-time worker is on. Residents have a choice of doctor, but they are encouraged to use the doctor predominately used by residents because of the paper work and because staff can better communicate with the doctor. We were told residents do go out by themselves - as long as they are physically able, the staff does not interfere. However, most residents seem to be hampered because of the physical limitations of the facility and its location - broken sidewalks surround the house and residents are not encouraged to go out because of safety. One resident told us, "I can't walk around outside because the sidewalk is uneven." The facility is also far from any shopping and stores, and the public bus stop is not close either. Talking about the difficulties getting out of the facility, one resident said, "We are dependent on outsiders." And another resident told us, "I would like to go shopping but I can't drive. What can I do?" All of the expectations of one resident's daughter are being met, except for enough activities - "people do not get out for fresh air - even a walk."

Privacy

Privacy is an issue in this facility. From the management's point of view the privacy of residents' personal space is protected because residents live in private rooms with doors that they can lock from the inside. However, the residents in the focus group we held said that they believed that the facility frowns on their locking their doors when they are inside. And the activity director believed that they were not allowed to

lock the doors. The administrator told us it is very hard to protect confidentiality of written information. Indeed we noted personal data tacked up on the activity room door for all to see: diets, doctors, dates of birth, and status. The administrator also told us staff often speaks about residents without realizing others can hear, and management is always working to prevent this from occurring. We were told that residents' privacy is protected during doctor visits – she puts paper over the window of the nurses' station as she sees the residents one by one.

Resident Governance

Even though required by State regulations, there is no resident council at this facility. The administrator told us that the active people are gone. The facility does have an open door policy regarding suggestions and recommendations. The activity director told us: "I ask for input constantly, but the attitude is to keep your mouth shut. Other staff also seek input. There are some complaints about the food." Again, based upon our experience with obtaining input from nursing home residents, there may be a number of barriers to overcome before these residents will speak up frankly and honestly: fear, apathy, loyalty and the lack of a belief that something will come of the issues they raise.

Although this facility seems to be struggling with how to counteract institutionalization, we found evidence that the facility could be doing even more and do a better job to meet residents' individual needs and support personal autonomy. One resident told us she accepts everything and is easy to please. We learned from her that she loves to read and listen to music in her room and reads whatever they have in the facility. She would like to go to the library or go to a concert but she says has not been able to -- she needs someone to take her but she does not want to put anyone out. This docile attitude could be a symptom of institutionalization and, if it is, she may need the help of the facility to make sure her needs are met.

A number of the residents did tell us they were happy not to be doing cleaning or cooking - they welcomed the release from those responsibilities. It may be that they are willing to exchange some decision making for less responsibility. However, feeling released from cooking and cleaning is of a different order from the learned helplessness the nurse was describing and that we observed.

Facility 6: Public pay, not-for-profit, suburban enriched housing

The Decision to Move to the Facility

Two of the residents we met with at a focus group meeting had lived in an adult home before moving here, and prefer living here because it is a more homelike setting and has a less disruptive resident population. The daughter of one of the women liked this place and helped make the decision to move here and the other woman's son works at the housing complex where the program is situated. Another woman in the focus group told us she was lonely and miserable and didn't know what to do and her daughter decided to place her here. During a telephone interview

with the son of one resident we were told: "My parents retired to Florida but Hurricane Andrew destroyed their home in 1992. They came to live with us. Mom developed Alzheimer's and had to be admitted to a nursing home. My father had the choice of living with us or somewhere else. We researched the choices and gave him a menu. He decided to come to this facility, mainly because he is a very frugal person and didn't want to spend more money than he had to."

Having Your Own Space

This enriched housing program is a tight living arrangement which does not provide the resident with the same kind of living arrangement as other enriched housing programs we saw, impinging on residents' privacy and lifestyle. This arrangement makes it difficult to accommodate individual personal care without imposing on the other residents. The independent residents are upset about the personal care aides that come in to take care of the other residents, and they are afraid the aides will steal from them. Even so, one resident who had lived in an adult home in a semi-private room before moving here told us how important it is to have your own space: "There is no comparison. Here I have my own room."

Choices/Control

The residents we spoke with all complained about the lack of choice related to food and activities. One resident said: "What I miss is the ability to cook the way you like. I was a healthy cook and I eat lots of vegetables. The food here stinks." It is possible that this is a reaction to the fact that the aides who cook are new; the former staff was here 14 years. They believe some of the food is pre-cooked.

The lack of activities was another major resident concern, and a resident also complained about the lack of space for activities. Staff meetings are held in the living room.

Facility 7: Public pay, not-for-profit, urban enriched housing

The Decision to Move to the Facility

Of the seven residents we spoke to during a focus group, five residents made the decision to move here. Some of the residents ended up at the program because they came through or were familiar with the nursing home that sponsors the program and thus did not shop around. One woman did look at many other places but chose this program because of its low cost and quiet environment. Two other residents were placed here by children and were given little choice.

One expected it to be nice and it was for one year until they changed the food; one man had no expectations - he was delighted; he came from nothing and was glad to have a roof over his head. One woman wanted security and found it. One woman expected it to be bad; she had been living with her daughter who died. She found it to be good; she likes the sense of community.

Having Your Own Space
This enriched housing program in New York provides its residents with their own apartments, and these residents therefore benefit from the independence that comes from this design. They can furnish their apartments as they wish, and we were told, are free to do whatever they want in their apartments.

Choices/Control
All the apartments have kitchens and residents join each other for dinner in a main dining room daily. This allows residents the freedom to cook for themselves, but not be burdened by having to cook every meal. The group dinner provides socialization as well but they are not required to eat the communal dinner every day - instead, they can go out or skip a meal.

They have other choices as well. They can choose their own physicians. They do not have an initial choice of home care agency but can change individual home attendants. They have many choices and options in regard to activities - they can attend any of the activities in the nursing home or the nearby senior center. The program also has its own activities. They are not forced to go to activities. The residents we met in the focus group meeting told us they feel independent at this program, and that they can do anything they want and feel they have lots of choices. The program also provides residents with greater financial power by giving residents a higher monthly personal needs allowance than is minimally required.

Resident Governance
The only problem residents seemed to have regarding choice is in regard to the food. To save money, the program has changed the food service program, which has limited the choices residents have. This is a major issue for the residents. Originally, the food was bought at grocery stores and menus were derived from the purchases. Now the facility gets its food from the nursing home that sponsors the program and the menus can only be chosen from those offered to the nursing home residents. They can no longer choose brands. One resident also complained that she did not like to have dinner at one specific time, and adjusting your eating habits to a strict, unvarying schedule is certainly a significant loss of autonomy for some people.

Although required by State regulations, there is no formal resident council. The social worker meets weekly with a group of residents to discuss issues and make recommendations. For example, residents requested updates on hospitalizations and provided ideas about increasing participation at meetings. However, residents told us that the one issue they are most concerned about, the food, cannot be changed and they feel powerless to do anything about it.

Facility 8: Public pay, not-for-profit, urban enriched housing ALP

The Decision to Move to the Facility

It is interesting to note, as opposed to other facilities, that most of the residents who attended the focus group meeting we held chose to live here and visited the facility before moving. It was the most attractive, if in some cases, the only option they had. Some residents were living with family who died or "had a life of their own". Others told us they came because of medical conditions and the inability to get around on their own during the winter.

Having Your Own Space

This is a facility that has adapted to the people who live here as a result of its history, population and management philosophy. The facility underlined how important and beneficial it is to have your own space, your own "home" within the facility. There seems to be a close connection between having your own place and maintaining a strong sense of self, independence, and autonomy. The residents in this facility are an independent group of people with strong personalities, and there seemed to be no question that the independent apartment design of this facility not only supports the personal autonomy of the residents here, but limits the tension and conflict that can inevitably arise in a group living situation. As the activities director told us, "the reason why this place works is because they have their own apartments."

Minimizing Institutionalization

The facility seems to try and balance the freedom afforded to residents by having their own apartments with safety concerns that arise with this independent living arrangement. The privacy of residents in their apartments is supported by the fact that residents have their own keys to their apartments. There is a master key that can be used to provide staff access to residents' apartments for emergencies and maintenance. If the maintenance staff needs access, they try and give as much notice as possible in an effort to respect residents' privacy. ALP residents have more limited autonomy and choice than their higher functioning enriched housing neighbors, however. Aides have keys to the apartments of ALP residents out of concern for the safety of these persons who are sicker or frailer. In addition, staff conducts nightly rounds of ALP residents. The nurse told us that some residents request not to be bothered when the staff conduct night rounds and these requests might be honored. However, out of concern of the dangers of residents falling in their own apartments, staff might not honor the requests of some residents who are vulnerable to falling.

Choices/Control

Besides the different treatment in staff access to residents' apartments, ALP residents do not have a choice of home care agency, due to contractual arrangements required under State rules. Enriched housing residents do have a choice.

In regard to other choices, residents have choices at meals, in common with all ten facilities we visited. Residents have their own physicians. In regard to other privacy issues, several residents in the focus group we met with complained about staff talking about them in the dining room as if they weren't there. We found this problem in other facilities as well.

We heard a few examples of the facility providing assistance and options to support autonomy and choice on a more individualized basis. One resident has a car and the facility provides case management services to help her maintain it. There is a woman who used to work as a waitress in a bar and is used to staying up late and taking her sleeping pill at 1:30 AM. The facility arranges for this.

Resident Governance

The resident council distinguished itself from council programs we saw at other sites because it is one of only two that are resident run. Half of the residents actively participate. They have their own officers and keep their own minutes. They focus on maintenance, food, and some minor decoration. The administrator told us, "They had input into the curtains when we redecorated. They were also involved in having the cigarette container outside replaced."

One resident provided us with a lesson on how assisted living can be empowering and enabling for residents. When we asked residents what was different about living independently, he told us in response: "It's very different. Outside you're on your own. I was in sight of the Museum; it was a stone's throw from where I lived. But there was a very busy street in between. You'd pick up a pocketful of headlights crossing it. The first time I was ever inside the museum was on a field trip with the home."

Facility 9: Public pay, for profit, urban adult home ALP

Resident's autonomy and choice seemed more limited at the combined adult home/ALP program. There are several possible reasons for this, including the higher acuity level of residents, many of whom also seemed institutionalized; the fact that many did not choose to live here on their own; and the neighborhood is unsafe.

The Decision to Move to the Facility

Most residents seem not to have been involved in the decision to come here, and several we spoke to do not recall how they came to be here. The marketing director told us that 98 percent of the residents came in crisis (a stove left on, a medical condition), and that there are residents here who did not want to come - it's the children that admit them (some, it seems, even under false pretenses. We found this to be the case at several other facilities we visited). The other 2 percent walked in on their own because they didn't want to live at home any longer.

Having Your Own Space
Most residents live in semi-private rooms. During our focus group meeting with several residents, one woman told us: "We have freedom here, but, it is structured. I can't do what I did when I was home." In discussing how it is different from living at home, residents said they lack privacy because most share a room with a roommate. One resident complained that her roommate had a man come in during the night and she didn't like it. This living arrangement also means residents cannot keep many of their personal possessions. One resident told us "There's a lack of closet space and we had to just leave many of our belongings." They also miss being able to go to the refrigerator at night for a snack.

Access to the outside community is limited because the facility is situated in an isolated, unsafe neighborhood and they miss being able to go out after dark. The facility supplies transportation for some outings; Medicaid pays for ambulettes to medical appointments and private pay residents pay for car service, but this seems inadequate given the facility's location and the residents' wishes. According to staff, the front door is locked all the time for security.

Minimizing Institutionalization
The facility tried to offer a life similar to a home in some ways. Although there are no kitchens in units (not allowed by regulation), they are able to garden and do some cooking (a cooking club) as an activity. Some couples have asked to room together and have been accommodated.

Choices/Control
Residents can have an outside physician or home care agency though not many do.

Resident Governance
There is no evidence of resident governance - the resident council meets every month but its only role is to allow residents to complain. Many people find themselves at council meetings because in order to get people to the Resident Council, the facility turns off the TV and holds it right before lunch outside the dining room. The facility has made some changes based upon resident suggestions. Residents asked for bagels and rolls and get them on weekends.

Facility 10: Public pay, for profit, exurban adult home for psychiatric and elderly residents

The Decision to Move to the Facility
In an informal discussion we had with six residents here, two residents told us that they had come here after being discharged from state psychiatric hospitals, one of which was being closed down. "I didn't want to stay in the City and the social worker suggested this facility. I came once and checked it out. Any place is better than a state hospital but it's brutal out there. I was like a little ball of fir when I came here. It took me a while to get used to it". Another resident told us he moved here when

the apartment building he was living in with his mother burned down. One gentleman told us he was "a casualty of Woodstock. We can live quiet lives here, nobody bothers you and there's plenty of time for meditation."

The one elderly resident we spoke to told us she developed a heart condition, and after being hospitalized "I got stuck in a nursing home and they started spending down my money. I told them I wouldn't pay them any more and they told me OK, but the only place that will take you would be this one. I've been here over a year and I really love it. I'd rather die than go back to a nursing home."

Having Your Own Space

Most residents in this adult home live in semi-private rooms. Each of these rooms does have its own bathroom. With semi-private rooms, this facility has to play the role of matchmaker. The facility pairs people up and the case manager told us that "sometimes it works and sometimes it doesn't." The facility seems flexible to some extent in working out roommate concerns. They tell residents to try it out for a week. If a resident cannot get along with anyone after six or seven changes in six months, the facility will not make any more room changes to accommodate the residents involved. The ten private rooms are reserved for private paying residents.

Privacy

Besides some privacy in terms of bathroom use, we were told the residents' medical records are protected because the facility does not have access to them. The records are kept by a County agency. Some residents, however, do not like the new TV cameras installed to monitor the cognitively impaired residents who are not confined to a particular floor of the building. One resident said, "I feel like an animal in a zoo. They watch us on TV."

Choices/Control

Residents have some choice in food in that they can always have a sandwich or cold plate if they do not like the main entree. One resident told us: "The chicken stew was bad but you can always have a sandwich instead." The activities program seems very rich and varied. There are sewing and cooking classes, art and poetry and discussion groups and games. There are trips and outings, and the public bus stops just outside the facility and costs only 35 cents. Although there has been some friction between the facility and the community, residents have good access to the community and are not isolated. The activity director said: "Many stay here only because they can go out to Dunkin Donuts and Rite Aid. One resident said to her: "Where they first put me, I couldn't get a candy bar."

Residents can choose their own doctors, and some residents do have their own doctor, but the facility prefers they not because it is hard to coordinate with them and they do not know the system. The case manager also told us that the mentally ill residents don't have to leave and go to day programs as in some adult homes. "We do require them to attend three meals a day."

Resident Governance

This facility has a resident council that meets monthly and attracts about 25 percent of the residents. The case manager told us that they meet once a month, elect their own officers and run their own meetings. "They complain about the food: 'The rice is too sticky'." We try to discuss facility rather than personal issues. It has no real power, but we try to work with them and most of their requests are reasonable ones." The facility has acted on some of their recommendations that include extra picnics and a pet bird in the craft room.

Risk Taking

Facility 1: Private pay, for-profit, suburban unlicensed facility

The unlicensed facility that we visited was somewhat of a contradiction. On the one hand, it tolerated behavior that some might consider risky such as walking down the major staircase in the building and drinking in rooms. The administrator felt that they are a social model and since residents and families who have toured the facility have seen the staircase, if residents fall, they are not liable.

On the other hand, if the facility feels uncomfortable that something is unsafe for the resident, it, like many of the other facilities, works hard to persuade the resident not to take risks it is uncomfortable with, and will call family if the resident insists.

This facility refuses to work with residents who still want to take a risk if persuasion fails and in fact may actually stop them physically. More than any other facility, the staff here will not only not help the resident take the risk, but will bar it. If a resident is diabetic, "we won't give them a candy bar, they'll have to go to CVS to get it. I will take cookies away from someone."

In addition, this facility saw nothing wrong with using the family to help them stop the behavior. They often call the family if a resident takes such risks. "We won't police but we will tell family." The direct care aides told us they "wouldn't allow it if a resident wanted to do something unsafe." The activity director said: "When residents choose to do things unsafe - 'I would say no.' I would persuade and reassure. I would be afraid something might happen. I would ask the family what they want." Residents confirmed that if they want to do something staff feels is unsafe, staff tries to persuade them not to. One competent man said, "The only way they punish us is to call our children when we are bad - they snitch on you."

Facility 2: Private pay, for-profit, urban adult home

The administrator and case manager of the licensed adult home use regulatory interpretation to deal with risk taking. They see a strong legal prohibition against limiting the choices of residents, and believe that they must allow residents to do what they want. This philosophy, however, is not shared by front line staff. Similar to other sites we visited, they were very uncomfortable with residents taking risks and perhaps hurting themselves. As we found in other homes, if a resident wanted to cross the street and staff felt it was unsafe, the facility might send a staff member with them if one was available. If not, the line staff might not let the resident go.

This facility has developed a more established, formal procedure in dealing with risk than other facilities. It has done this in order to balance the administration's belief that the regulations require facilities to allow risk with the staff's uncomfortable feelings about allowing residents to do things they believed unsafe. In cases where line staff is unsuccessful in restraining more risky choices, staff goes to the case manager and it is discussed at weekly interdisciplinary care conferences with department heads. The case is documented and residents are asked to sign that they were informed and then, if they still want to do something considered unsafe, the facility's management believes they must be allowed to.

Considering the fact that maintaining control over one's own life is seen as a basic tenet of assisted living, it is interesting that in this facility, as well as others, family was often used to help staff deal with residents who would not listen. The administrator said "if really dangerous, I probably would not let them and would call the family." Thus, the presence and attitudes of family members may limit risk-taking on the part of the resident.

Here as in other facilities, we found that many of the residents we spoke to felt they would not do anything unsafe - staff knows best and they wouldn't take a chance.

Facility 3: Private pay, for-profit, urban unlicensed facility

The notion that in the end, there was nothing staff could do to prevent residents from doing things that subjected them to serious risks was something that was acknowledged by both residents and staff at the unlicensed facility we visited. This seems to be due to the fact that the facility in general has a lax management style and the seeming lack of organization and accountability limits the ability of staff to control the behavior of residents, even if they were so inclined. In the absence of any established facility wide standard, individual staff seem to do what they think

is right. For many, this means calling family. The residents we spoke to in our focus group seemed to confirm this. They told us that they can come and go as they like and eat what they like, and that if they wanted to do something staff feels is unsafe, staff can't force them not to, although their families would. This seems to indicate that some staff use family to police residents' behavior.

Some staff here believe in the resident's right to take risks but will not agree to everything if they feel directly responsible, could be held liable, or if they feel it is too dangerous. The activity director told us: " I can't tell them no," if, for instance, a resident wants to go for a walk or eat sugar. "However, one time we went to the beach and were on the boardwalk. The residents wanted to go down to the sand and into the water. I said no. I would not take that responsibility." While there were other staff at the facility who do call family, a pervasive practice in many of the sites we visited, she did not believe in calling family. "These are adults. I would not call their family. They have the right to make decisions."

We did get the sense in some of the places we visited that families can put pressure on facilities to control residents' behavior or actions. The activity director at this facility said, "We sometimes have trouble with the adult children. One resident has a boyfriend. The family doesn't like him and wants us to separate them. I explain that they are adults and can do what they want." A family member we interviewed whose uncle lives in this facility told us her uncle wanted to bring his exercise bike here at the time he was moving in. She told him the facility would not let him take it. In fact, she had never asked the facility, was afraid he would fall off and so she made the decision for him.

Facility 4.: Private pay, not-for-profit, urban enriched housing in a hospital integrated delivery system

At this licensed enriched housing facility there is again no formal risk sharing. Independent units and state regulations make this irrelevant in this hospitality/non medical model facility because as enriched housing, residents are automatically assuming risk, but even more so, because it has defined itself as a hospitality model offering a narrow band of services. The facility appears to be on "the other side of the line" in terms of housing arrangements with services where the facility itself is not totally in control and thus faces more limited accountability for what happens to residents. It therefore seems less preoccupied with risk-taking than other facilities or programs.

Residents come and go as they please. If the risk taking poses a danger to a resident, such as refusing medications, and it is a pattern, they document and call the doctor. They discharge residents quite quickly. The typical length of stay is about half of that of the other facilities. They counsel and educate residents and sometimes meet with families. The administrator told us, "We can't tell the diabetic what they can't do but we can reason with them." "We can't tell them they can't have something." If a

person is a wanderer, they will pull staff to go with them outside. In some cases residents were putting a teakettle on the stove with no water. The facility spoke to the resident and family, added an addendum to the agreement to disconnect the stove, and all have had to sign it. The activity director worries about residents getting lost even after all the documentation. 'I have to be careful I don't hover too much. I watch from a close, safe distance."

The daughter of one resident told us that risk-taking is handled on a case by case basis. Her mother is on a salt reduced diet but she likes hot dogs. The daughter has called the doctor to write a note and document by phone or fax for the facility so that she can have the hot dogs. Her mother has also refused services in the past, and the facility calls her in those instances. Once, she was refusing to take showers at the scheduled time, possibly because her chemistry was fluctuating, and it affected her mentally. The facility tried to address the situation with her and then called the daughter. Another relative we spoke to told us that her mother is capable of refusing services, but never has. "She did refuse surgery for arteries while at the facility, but nothing like refusing medications."

Facility 5: Public pay, not-for-profit, suburban adult home

The not-for-profit adult home we visited seemed to be one of the more risk adverse facilities we visited. This seemed to be related to the feelings of staff. The administrator remembered one instance where they used a formal risk contract, but it was only drawn up to allow the facility to state they would not be responsible. Besides this one instance, there are no formal risk contracts or policies because it would be too hard to develop policies. "We couldn't deal with a vehicle to allow risks as a way of promoting autonomy." Instead, the facility's approach seems to be on an individual case by case basis. If residents want to take a walk around the block, with one resident it might be okay, with another, it might not be. This facility tended to try to persuade the resident not to take risks or tried to have a staff member accompany the resident to avoid risk-taking behavior. Here too, staff seemed very uncomfortable with residents doing things they considered unsafe. In some instances they have asked residents to leave if the residents continued to do such things. The process at this facility is informal: staff speaks to residents and try to dissuade or provide alternatives.

In this facility, the ability of the staff to permit risk taking seemed to relate to the immediacy of the harm that could befall the resident rather than risk-taking in general. For example, one man was somewhat disoriented, but was capable within the facility with constant cueing. He loved to walk and he would walk around the neighborhood, walk out in the middle of the night and wouldn't know his way around - he thought he was inhis own neighborhood. The family was willing to allow him to go out, but the facility felt it could not keep him because he could be hurt. Another resident with emphysema is not allowed out on high ozone days even though she wants to be outside. However, a resident who is on medication that makes it

dangerous for her to get too much sun sunbathes all the time. The staff tried to talk her out of sunbathing but she was adamant - "This is what I want to do with the rest of my life." They let her do it. She is getting skin cancer, but "we can't force her to stay inside". "We try to get her to use sunscreen and conducted an in-service for residents and staff." It may be that if the risk is immediate (an individual can get lost and can get hurt now or ozone levels can harm immediately) the facility will not accept it, but if it is not immediate (sun bathing may lead to cancer but not immediately), the risk can be taken.

The process of persuading residents not to do anything staff believed unsafe and not to take risks seemed to have an impact on many of the residents. We often found at the sites we visited that many residents did not want to take risks. One resident at this facility told us: "If staff explains to me why they do not want me to do something, I would agree." It may be that this represents a shared belief or a community norm freely held by both residents and staff. It may, however, be a result of staff who spend so much time trying to persuade residents not to take risks, or the result of residents' "institutionalization" and their abdication of decision-making responsibility to others.

Some of the residents are homebound. The administrator and activity director told us they will refuse to go on outings because they are afraid of falling, that it is too far away, or that a bathroom will be inaccessible to them. Still the facility makes an effort to encourage residents to take risks in the form of going out on trips. They were successful in getting them out to a kindergarten graduation one block away with children that are part of the inter-generational project they are involved in.

Facility 6: Public pay, not-for-profit, suburban enriched housing

The enriched housing program is housed in a few garden apartments, situated amid hundreds of others. For the enriched housing model in general, the lack of 24-hour supervision as well its non-institutional nature leads automatically to the assumption of risk by the residents. Aides go home at the end of the day and residents are on their own and can do anything they want. It does not appear, however, that there was any planning on the part of the program and its sponsoring agency for the growing dependency of the residents. Most of the residents have long lived here and the sponsoring agency seems to have been caught by surprise. One could question whether the residents and families really understood the risks they were assuming in moving here. Thus, for both the residents and the facility, risks are assumed without foresight, perhaps because this program has existed for so long with the same residents. Because this program has not been able to as yet adequately meet the growing needs of their residents, risk taking is an on-going preoccupation of the sponsoring agency. Staff seems to react to risk taking as they crop up. For example, one resident who had become more disoriented in the opinion of staff wanted to go to an adjoining county to do shopping. Staff spoke to her, to her daughter, to other residents, but she went, causing worries for all of these parties about her late return.

Although this facility seemed to react, rather than plan, for risk-taking as people deteriorated, it worked hard to allow residents to take risks and is trying to deal with the issues that arise. The facility continued to allow the disoriented resident who went shopping in an adjoining county to take risks by finding ways to make her risk-taking safer. She wanted to go to a conference but staff knew the resident was not good at remembering to take her medications, and would then end up being hospitalized. The staff packed the medications and worked out arrangements to make sure someone reminded her to take them at the meeting. The staff felt strongly that she had a right to go. The nurse told us that staff would intervene if someone were in immediate danger, but people have the right to make bad choices.

We were told the philosophy of the program is one in which residents should be allowed to make choices as much as possible, and that by assigning staff to go with them, as an example, those choices should be honored but assisted in such a way as to make them as safe as possible.

Facility 7: Public pay, not-for-profit, urban enriched housing

The enriched housing program was one of the more risk adverse facilities we visited. Staff seemed very concerned about the responsibility they had to keep people safe. They found it difficult to live with resident risk and they seemed more likely to urge someone to go to the nursing home if things seemed unsafe. Although we were told by the program's administrator that alert and oriented residents can take risks, one alert resident told us that he had to fight for the right to go out to the store in his wheelchair.

This program seems to have a more involved process for managing resident risk than most other programs or facilities that we visited. They have team meetings, try to understand why the resident is taking risks, provide education and counseling and speak to the residents' physician. If in the end the resident will not adhere to the program's parameters or the plan of care the staff believe is necessary, "they may have to go elsewhere. We are responsible for their well-being." An example of this was a resident who was not eating. They asked for a medical work-up and family meetings. The resident moved out to another apartment, presumably because no agreement could be reached about the need for additional care or nursing home placement.

However, the program has also worked hard to keep individuals where staff believe they can live with the risk. As an example, the administrator of the program discussed the case of a resident who is mentally slow and has asthma. She is concerned about his ability to use his ventilator. She also believes he would be better off with air conditioning, but his family has refused to provide it. He remains in the program because of his family's insistence and because the rest of the staff are comfortable with the situation. In another example, the daughter of a resident

described to us how her mother came to the program. She was originally in the nursing home, but was miserable because she could not get used to its institutional regimen. At first, the nursing home and enriched housing staff didn't want her to leave the nursing home. The daughter said, "They were worried about her balance and they were concerned about their liability. We argued that it was better to live your life and take the risk. I promised I wouldn't sue them if she fell." The daughter believes the program continues to be flexible in that her mother isn't attending the required dinner meal any longer. "She is theirs now and they are committed to enabling people to live their life." Her mother does have a home attendant 10 hours a day and that may be helping the program live with the risk.

There is a stark contrast here between the very protective atmosphere of the program during the day and residents' freedom or lack of protection at night. One woman fell off her bed reaching for something during regular hours. Because a staff member happened to be in her room and saw the incident, she insisted on calling the nurse even though the resident said she felt fine. The nurse, in turn, insisted on sending her to the hospital even though she did not want to go. If an incident occurs after hours, however, a resident pushes the call button, which connects to the security guard in the lobby. He then calls 911. Thus, if this resident had fallen off the bed after hours, she probably would not have called anyone and would not have been sent to the hospital.

Facility 8: Public pay, not-for-profit, urban enriched housing ALP

This enriched housing/ALP has developed its program around the "normal" life of its residents, and in the process, has created a facility that promotes independence and empowerment among the residents. The administrator says she does not want to be a "warden": "These are adults and we're not running a kids program."

Risk contracts are a foreign idea for this facility because the facility does not perceive itself as an institution that exercises control over residents nor, as a consequence, has the resulting legal liability for their behavior. The unique characteristics and "culture" of the resident population has helped determine the agency's attitude and defines to a large extent what is acceptable as a risk: "We are dealing with a population that have been risk takers all of their lives. Heavy drinking, abusing drugs, gambling, tinkerers with safety hazards in the apartments that upset inspectors." A good number of the residents have obviously operated outside the conventions of middle class conduct all of their lives, and were variously described to us as misfits, loners, street people and survivors. The administrator told us that many are estranged from their families and because there is almost no family involvement in their care there is no one other than the resident themselves that needs to be placated or would raise a source of concern over litigation should the risks taken by residents turn against them. There are no rules and restrictions other than those established by the State, County and the housing authority, such as smoking and life safety. The administrator indicated that because resident risk-taking

can't be open-ended, these externally imposed limits on what can be done are necessary and welcome. Staff gave some examples of residents' autonomy and risk taking. There is a legally blind 90-year-old lady that has an antique lamp that she uses to hang clothes in her apartment. The facility was cited for a violation by a fire inspector for this. The next time the inspector came she took out a scissors, clipped off the plug from the cord and said, "There! It's a coat hanger now and not a lamp!" If medical regimens or dietary restrictions are not followed, the program's procedure is to notify physicians.

Facility 9: Public pay, for-profit, urban adult home ALP

In contrast to facility # 2, the combined adult home and ALP program feels state regulations stop them from allowing people to take risks, and limits resident autonomy. They may be interpreting the regulations in a way that falls heavily on the side of their perceived responsibility to protect the well being of residents. Similar to other assisted living facilities we have visited, this facility tries to talk residents out of risky behavior. They do counseling with diabetics with a social worker and will also refer them to the doctor. There are a few residents with dementia who are not allowed out. They discourage some residents from going on trips because of the risk of falling. There are other residents who do not go on trips because of their mental disability - staff know they are going to get lost. They would stop people who insist on risky behavior. They do try to allow residents the freedom they want at times. Sometimes residents are allowed to go out if the facility calls in extra staff; they may send a staff member with someone who wants to go out and is unsafe. They even pay other residents to accompany residents in a car service to keep an eye on a resident they are concerned about. This facility also calls family for help in dealing with residents who want to take risks, but this seems to be done less than at other facilities. The administrator told us that they would notify the family even if the resident were intact. If a resident asks the facility not to inform the family, the facility will anyway in order to protect themselves. "The state would tell me the same thing." We found that most residents wouldn't do anything unsafe.

Facility 10: Public pay, for-profit, exurban adult home for psychiatric and elderly residents

At the adult home facility with mentally ill and elderly residents, the long legal battles over the rights of the mentally ill and the growing protections against involuntary commitments have influenced risk sharing for the frail elderly. As the Case Manager told us "Residents are free to do whatever they want." Residents here have the right to take risks and staff understands this, working with the residents to try to support this right.

Since a main attraction of the facility is its close proximity to town and its accessibility to places like snack shops and pharmacies, there is plenty of traffic in and out of the building. Persuasion and offering options (such as escorts for trips) are

used if it seems risky for that person to go out. For example, the activities director told us she has walked more than one resident down the road to the snack shop and the case manager said that the facility tries to coordinate local trips to meet residents' needs. The administrator takes precautions by putting up signs during winter snows asking (but not forbidding) residents not to walk in the streets. But if a resident wants to take the train down to New York City, the case manager told us, "We can't stop them." If all the efforts to dissuade residents from risky behavior fail, the facility and the County Mental Health unit simply document these efforts and hope for the best. This applies to medical care as well. The case manager told us "We can't stop them from refusing treatment." One resident is presently refusing treatment for a tumor. The facility is counseling him and keeping a record. Family members and adult children, because of their absence play no part in this process. There are no risk contracts, but the facility will help residents plan a budget to avoid problems that might arise from taking large sums of money out at one time. "We try to discourage residents from taking a large amount of cash out of their personal accounts, but that's all we can do. If we give them all their money at the first of the month and they run out in two days, we try to give it out next time on a weekly basis and, if this doesn't work on a daily basis."

CAREGIVERS: A STRUGGLE TO KEEP THE PROMISE OF ASSISTED LIVING

Staffing

Facility 1: Private pay, for-profit, suburban unlicensed facility

This facility lowers the hours aides work if the facility's occupancy goes down, a practice we found at one other facility. Turnover of staff may be an issue here because the two health care aides we spoke to were both new, having worked here for 4 and 6 months, and the executive director of the facility told us they interview for aide positions on a weekly basis. Staff we spoke to has experienced backgrounds. The facility pays $9 or $9.50 an hour and hires only certified home health aides. They provide additional training.

Both health care aides told us they love working here. They like the staff and view the facility as their second home. They believe the work place is organized well to help them do their jobs better and that there is teamwork among the staff. They are empowered to adjust their own schedules when they have to. They feel they have good communication with the director. One aide likes the fact that residents have everything in their rooms (supplies) unlike what you find in a nursing home. There is a "lead" health care aide who helps as the shift changes - she gives us verbal and written points. "There is a buddy system here. We change shifts for each other. We are given a list of aides to call if we cannot come in." Apparently, this does not always work because one of the issues they mentioned was working short staffed if someone calls in sick.

Facility 2: Private pay, for-profit, urban adult home

The staff here did not express and did not seem to share many of the issues workers from other facilities raised with us. The receptionist, waiter and housekeeper we spoke to all have long tenure in the facility. They enjoy the environment and find it a good place to work. It provides a warm family atmosphere for staff as well as residents. What they did share with many of the other workers was the enjoyment and satisfaction working with the residents. The personal care aides we spoke to said "the happy part of the job is the talking and relating to residents." Like other workers elsewhere, these aides said there were also difficulties working with the elderly. They told us you need patience with the residents. Some refuse to shower and eat. Some residents get short with the aides. They also told us that sometimes the problem is with the relatives and not the residents. This was something we did not hear at other facilities. "Some have an attitude toward the aides and you have to win them over. Sometimes they complain about the way we dress them when the family actually needs to bring in clothes for them." While no one voiced any complaints about wages, after 19 years, the housekeeper is paid $10 an hour, which seems low given her tenure here.

Many staff, including the staff here, told us that one of the most difficult problems they face is watching residents deteriorate. Given the close relationships many develop with the people they care for, watching residents age-in is hard on staff emotionally: "I was with this one resident for years. One day when I was washing her, she turned around and said, 'I wish you could have been my daughter.' and she hugged me and died right on my shoulder. I was hysterical and I cried and cried for hours."

This dedicated personal care staff was well aware of the irony of their situation. They try to provide the empathic care they would want to receive, yet they know they will never be able to afford the care they are providing: "you are going to be there someday and whatever you do in life, one day somebody is going to do for you. They are a mirror and you can see one day what you are going to be. I want the same care I am giving, but I'll never be able to afford it. The best I can expect is a space in the parking lot!"

The personal resident care is provided by two licensed home health agencies. The aides were all trained before coming to the facility. They all paid for their training. Staffing seems adequate since they each take care of about 7 residents.

Unique to this facility and one possible reason why staff seem more satisfied here is the evolution of staff roles, teamwork and cross training of staff. The evolution of the roles of various staff and the organization of care has involved an inventive adaptation to the needs of residents from what was originally developed to create the ambiance of a resort hotel for a healthy adult population. The receptionists now serve

as the nerve center, coordinating the care of residents. They schedule doctor appointments, make sure residents get to these appointments and assist residents with medications. Any issues that are observed are communicated to the case manager.

The waiters and waitresses also receive personal care training and monitor the eating habits of residents, encouraging and guiding good nutrition. The Maitre'D periodically weighs residents before meals and keeps track of those that don't come to a meal, making calls to the rooms of "no shows" to encourage their attendance and making sure that something is sent to the room and that other caregivers are alerted. The room attendants or housekeepers are also trained as personal care aides. They monitor various issues such as incontinence, bleeding, and possible adverse reactions to medications, doubling almost as floor nurses. These assignments appear to have evolved from the regular monthly meetings of department heads that focus on interdisciplinary problem solving. The fact that many staff have dual roles that seems to make their job more satisfying contrasts with the problem staff have at an enriched housing program (see below), where staff find themselves fulfilling other job responsibilities on a frequent ad hoc basis.

Facility 3: Private pay, for-profit, urban unlicensed facility

We spoke to two aides at the unlicensed facility. Like many aides we met on our on-site visits, they were relatively new, leading us to believe there is considerable turnover at many places.

Issues of wages and benefits seemed to be of concern. One aide is paid $7.50 an hour. Both have had experience with private duty cases and both like working with the elderly. They work 12-hour shifts (7 to 7). One works 48 hours a week (overtime pay is time and a half); the other works 72 hours a week. They get no benefits, though the facility is looking to give vacation time.

The aides' low wages is an issue for them and they do not plan to remain here long. One said, "When I was responsible for one person I got $7 an hour. Now I am responsible for 16 people and I get $7.50. I am plan to go back in the Armed Services, I want to become a nurse. There is no pension plan here, there is no future here, but I'd rather be here than in someones' home caring for one individual. You learn more. I am young now and working 72 hours a week, sending money back home, but I can't keep this up. I'd like to get the education and become a nurse. " The other aide also likes working here but plans to leave to go to nursing school. About the nature of the work she said: "Nothing is difficult and the people are nice. We respect them and they respect us. They both agree that they could never afford the facility if they needed it.

Facility 4.: Private pay, not-for-profit, urban enriched housing in a hospital integrated delivery system

At this licensed enriched housing program, the working conditions of aides are an issue. Here, staffing is lean (according to both the administrator and other staff), a group of dedicated aides shoulder the burden of working with other aides who are far less responsible, and at times, aides take on other department staff responsibilities. According to the nursing director about 50 percent of the aides are excellent. She told us that these aides work hard, feel frustrated and don't get a lot of respect. They need praise and recognition. For the others it was just a job and they are very negative. This created morale issues since the aides who are excellent end up having to cover for the others. The nurse also told us that there are racial tensions between the aides and residents, which is something we heard at an other facility we visited.

Its lean staffing comes as a result of the business model the facility and its operations were designed around: a small profit or surplus bought with a tight design in terms of floor space in the apartments and common areas and tight controls on staffing. This is discussed in the section on Finances.

The aides we spoke to talked about the same theme: they are frustrated at the lack of teamwork and the fact that some aides don't pull their own weight. "When I have to work on weekends, I want to know who else is working." They feel they are forced to fill in where staffing is limited. "We need a receptionist and activities director on weekends. We end up filling in for both. We also end up fixing stopped toilets, etc. when we can't get maintenance to come. We end up helping out in the kitchen which also adds to our duties."

The other theme the aides touched on had to do with respect and recognition. They feel they get some but not enough. One aide who had worked for the hospital on campus said, "There needs to be a way to give more recognition and a pat on the back to aides. We had educational programs and in service training at the hospital - we should have similar opportunities here. The residents do give us a bonus at Christmas and the picnics where we bring our families are nice."

Most aides here work for $6.50 to $8.50 an hour. One aide who works the evening shift and has been with the facility 5 years earns $10.50 an hour. Another aide who has been with the organization many years, working in its hospital and nursing home, now earns $9.50 an hour.

Facility 5: Public pay, not-for-profit, suburban adult home

The adult home impressed us as a good place to work, which seemed to be the result of at least two things. First, there is a caring and stable staff who, according to the nurse supervisor, "are classy and have a high ethical construct providing direct patient care." She also said the facility had no problems hiring and keeping good

staff. "It's a combination of a congenial environment and people in the area that have access to transportation." Secondly, the dedication and good will that the staff exhibit caring for residents is recognized and supported by a management which is protective of the staff and concerned about maintaining good morale. This means that even though they are taking care of frailer residents they are careful that who they admit and retain does not overwhelm the staff.

We had the opportunity to speak to two aides at this facility and they explained the lack of staff turnover from their point of view: "We have a good administrator. We can approach her whenever we want (we observed this in action during our visit). Her door is always open. She cares, is straightforward, makes quick decisions and fights for us. We are like family."

They said the most difficult problem they face is when residents start to deteriorate. "We expect it but don't accept it." "We get very close to the residents." Seeing the loss of independence and knowing there is little they can do is painful for them. They like working with the elderly - "What you give, you get in return."

One aide has worked in a nursing home and as a home health aide. She has been at this facility 30 years and works full time. The other aide worked for 4 doctors doing private cases. She works part-time, 3 days a week/ 8 hrs per day and is paid $9.50 an hour with health benefits and no pension. She's been here 3 years.

This facility provides useful and interesting contrasts to some of the other facilities where the workers and management do not have as good a relationship. Another facility, an enriched housing/ALP empowers their residents at the expense of staff. Is it fair to ask, given the limited autonomy residents have here, whether staff are being empowered at the expense of residents? Unlike two facilities that cut worker's hours if vacancy rates climb, staffing here is based upon full occupancy, which the facility has been well below for some time. It did not cut staff as its census was reduced because, the administrator told us "if the census goes up, how will the facility get needed staff quickly?" One other facility bases its lean staffing pattern on a strict business model that impacts on the staff with seemingly little concern from management in contrast to the homelike nature of this facility, both in physical appearance and level of relationship between the people who work and live here.

Facility 6: Public pay, not-for-profit, suburban enriched housing

The enriched housing program has gone through considerable reorganization as a result of the aging-in of its residents. It is clear that the program needs to change to make sure the needs of residents are met. Systems need to be put in place for resident assessments, checking on the administration of medications, communication with physicians, and the supervision of aides. An activity program needs to be established. Because of this reorganization it has experienced considerable turnover. Personal care aides have been hired directly by the residential program rather than contracted

with the sponsoring agency's home health agency. This has given the program more control. A part-time nurse has been hired to develop systems for the oversight of medication administration and care needs. The program faces a choice of expanding to 24 hour staffing or placing some of the residents with more extensive needs elsewhere.

There are 2 aides that share the job - one works for 3 days and one works for 4 days. They receive $10 an hour. These aides cook, shop, clean, give out medications, document medication passes and other issues, and do some personal care as needed. The aide we spoke to told us that often when she is cooking dinner, the incontinent resident has a bowel movement as she is coming down the stairs. The aide must stop and clean her up and then go back to cooking. She seems to know how to record these instances and how to let her supervisor know about them. Previously she worked with computers as well as with a home care agency but she told us this job is different and she likes it much more. "I want to be here when I get older. It's like being at home. I look forward and feel good about coming here in the morning. I thank the Lord."

Facility 7: Public pay, not-for-profit, urban enriched housing

We spoke to two aides at the enriched housing program, and as in other facilities we visited, wages and workplace practices are issues here as well. One aide is new, having been with the program one year and is paid $5.68 per hour, and one has been with the program 4 years and is paid $7.75 per hour. If the program does not have all of its apartments filled, they cut the hours of the aides, which is a practice we found in one other facility. They felt it was hard to keep good staff - one man quit because he couldn't live on the pay; another was let go because he could not work on weekends. However, they did feel there have been a lot of improvements at the program -- "They are making it a lot easier with full-time hours. They are trying to be fair - now we don't have to work weekends all the time, but we take shifts" -- so it seems the program is beginning to respond to some of the concerns that may create turnover of staff.

The most difficult part of their job was the complaints from the residents, particularly the issue of food, which we have discussed elsewhere. The residents get upset and take it out on them. They also told us that the residents get frustrated - they want to be independent and hate to need help. They try to keep residents calm and happy.

Facility 8: Public pay, not-for-profit, urban enriched housing ALP

The friction between aides and the residents and supervisors was the only recurring sour note in this otherwise very attractive program. As we've discussed in the sections on Autonomy and Risk-Taking, this program has been built around and remains dedicated to supporting the decision-making power of a very demanding, impoverished population. However, the empowerment of residents and the degree of

resident control has been purchased at the cost of much less sense of control over working conditions by the aides. The aides we spoke to felt the facility had an ad hoc character that gave them little control over the demands of residents. Supervisors would say, "give them what they want." The aides also told us that the residents at the facility "put on airs and don't need as much care as they think." They also felt the facility lacked structure because of the open-ended nature of their job that involved an expansion of their duties. They were particularly troubled by the addition of serving and helping with the preparation of meals, which had been added to their jobs. Among the several things they would like to see changed is respect from residents; other staff really listening to the aides; and to be backed up more by management and have a less open-ended job description.

The other striking thing at this facility was the fact that good services to a low-income population may have been purchased at the cost of taking advantage of others in poverty, because the one other major complaint aides voiced were their low wages and limited benefits. It's a complaint raised by many of the other aides we spoke to during our other site visits. At this facility they work a part-time schedule of 30 hour, 4 day shifts at $7.14 an hour. They receive $89 a month extra for health insurance. They would like a higher hourly pay and a full time work schedule.

Facility 9: Public pay, for-profit, urban adult home ALP

The three direct care givers we spoke to in the adult home/ALP program love to work with the residents. They feel needed. Two of the aides work for the ALP program, and the other aide cares for adult home residents. One aide has been with the facility 21 years, another almost 2 years and the third, 4 months.

The aides said their major difficulty as care givers was dealing with the moods of the residents and the psychosocial aspects of aging. "Some wake up unhappy and take it out on us. They don't want to take showers. We try to accept it and give them space - we can't force them, if we do, our job becomes harder." Another told us, "We need to have patience." The nurse supervisor agreed that the biggest problem for the direct care staff was having them understand the residents. "Most have dementia in the ALP program and the staff have to accept dementia characteristics - how to deal with demented residents. Even though they are here, they are not in prison. We can't set all the rules."

Facility 10: Public pay, for-profit, exurban adult home for psychiatric and elderly residents

At the adult home for the mentally ill, aides receive $7 an hour, and pay, according to the aide we spoke to is her major problem with the job. (It's the first thing she said when she sat down with us). She regards the job as manageable, but with responsibilities that would seem to warrant higher pay. She is a single mother supporting three children, can't afford the optional benefit package and her children

are covered by Medicaid. She left once for a job at a nursing home with higher pay and returned once the pay here was raised to $7.00. "I've grown very attached to some of them. I love them and that's what keeps me here. At a nursing home I could get $9 an hour." This seemed a common theme for other assisted living workers. They prefer the assisted living model to home care or nursing home work (offers more varied work experiences and an opportunity for interpersonal friendship and bonds; aides get to know residents as people and not patients) and grow very attached to the residents, but may have to leave the job for higher pay elsewhere. The personal care aides assist with the medications, bathing, dressing and toileting.

Finances: Two Tiered Levels of Assisted Living Care
Public Pay: Endangered Species

Facility 1: Private pay, for-profit, suburban unlicensed facility

This facility accepts only private funds and is at 100 percent occupancy. This is a facility that has a range of charges and services. If a resident runs out of money, they are discharged. According to the administrator, most residents have enough money for 5 or more years. It charges from $2500 to $5000 for an apartment, meals and activities. Anything else is extra. An assessment and care plan is made (individualized service plans) and cost is determined by point values of the care they need: personal care has three levels for cognitively intact residents and ranges from $23 a day to $56 a day.

For the cognitively impaired, the facility's special program is divided into two levels depending on care needs. The cost ranges from $ 53 a day to $65 a day. Administration of medication is extra. During our focus group meeting, residents expressed upset that everything costs extra.

Facility 2: Private pay, for-profit, urban adult home

This facility does not accept SSI and insists on the full payment of its private rates. It has no sliding scale. The facility does not inquire into financial resources because if money runs out, the individual is discharged. In rare cases family members have chipped in to support SSI/Medicaid eligible residents. Individuals often spend down and have to move from private to double occupancy. The personal care services add to the cost. Typically residents that spend down have incurred large personal care costs and are transferred to a nursing home on Medicaid. For those that do not meet the nursing home criteria, family conferences are called and payment arrangements are worked out with the extended family, if possible. If not, they are discharged to a facility that will accept SSI While no detailed documentation is required, those that appear not to be able to cover the cost of at least a three to five year stay are guided elsewhere. These arrangements appear to work, since no one has been forced to leave because of nonpayment over the last decade.

Rates range from $1,800 for a semi-private room to $7,000. In addition, residents who need basic personal care (dressing, bathing, and being brought to meals) may purchase cluster care at an additional cost. Residents can also opt for one or more hours of one-to-one care. The administrator told us "We have the best care if you can afford it." He is familiar with what every one else does in pricing various services and at this facility they do not believe they should nickel and dime people to death (e.g. charges for licking stamps, rental of TV stands, etc.). He thought families resent this, and as we found elsewhere, so do residents.

Residents here have suffered other indignities however. During our focus group meeting with several of them, most began the session talking about how nice it was to have a roommate and how reassuring it was not to be alone. It later became clear that most had begun with private rooms and the major factor motivating the shift to double rooms was affordability. One was quite angry and defensive about this. When asked for the reason for the shift to double rooms one replied, "come on, didn't you go to college?" The implication was that the answer was obvious and it wasn't nice to ask.

Facility 3: Private pay, for-profit, urban unlicensed facility

The unlicensed facility is run like a hotel and leases its rooms on a month to month basis. It accepts only private paying residents who are charged $1,600 a month for a semi-private room, $2,350 to $3,000 for a private room, and $3,500 for a suite. These charges include room and board, house keeping, 24-hour security, coach/van for regularly scheduled events and the activities program. Care services cost extra. According to the administrator, those who run out of funds will be assisted in seeking other care, (since this facility is unlicensed, it does not have to do this) although that has never happened. It is just in the last couple of months that the facility has attained a 95 percent occupancy level and has begun to turn a profit.

An outside home care agency bills on a private fee basis and none of its services are reimbursable by Medicare and Medicaid. The additional personal care services can add up, totaling in the case of the dementia care patient well over $5,000 per month. Yet, the reality is not quite as simple as such payment arrangements suggest. The home care agency provides some care to residents that they are not receiving any payments for and some of the residents that clearly require additional personal care don't receive it, perhaps because they cannot afford it. The staff from the home care agency and the facility administrator acknowledged situations where residents were assisted without charge, creating a murky area where residents were getting some of the assistance that they needed on a patchwork basis but lacking adequate care. Focus group residents also complained that they felt they were subsidizing some residents who could not afford extra care because they were paying for care and others were not.

Facility 4.: Private pay, not-for-profit, urban enriched housing in a hospital integrated delivery system

This facility has yet to face the problem of residents who have exhausted their resources and in the event of such an event, "we wouldn't throw them out on the street, but we would aggressively search for other options." The facility has priced its units from $2,400 to $3,000 per month with no additions for the additional needs of residents. Residents do have the option of hiring private personal care aides and nurses, if necessary, but this is arranged privately through the family and typically takes place while awaiting placement to more appropriate settings. They have been careful to price themselves competitively with other options in what is clearly a very price sensitive market. This is tightly budgeted and staffed operation that caters to a middle-income market.

This enriched housing program has always turned a profit, fulfilling the goals that are typically established for such new products by health systems such as the sponsor here: providing additional margin to help with the overall bottom line and helping to shore up acute hospital admissions. Even though this facility caters to the private so-called "high end" market it's annual profit or surplus is probably less than $50,000 per year and bought with a tight design in terms of floor space in the apartments and common areas and tight controls on staffing which, as indicated in the staff interviews, has created some friction with staff and perhaps even residents.

If nothing else, the flat per month payments and narrow operating margins financially discourage admissions of any residents with complicated care needs or aging-in place. It encourages rapid discharge of residents whose needs exceed those allocated by the staffing patterns in the facility.

The flat monthly rates also require careful screening of prospects for admissions. Since this is a licensed facility, it is required to develop a discharge plan if it wants to discharge a resident. It must attempt to admit only those residents who can afford the rates because it may be difficult to find alternative placement if finances run out. There is a financial form for listing the combined sources of monthly income and assets that must be sufficient to assure that the resident can self pay for three years. Private long term insurance has not been a factor in assuring financial ability to pay. There have only been two individuals in our five years of operation for whom private long-term care insurance assisted in paying for their stay.

Facility 5: Public pay, not-for-profit, suburban adult home

The non-profit adult home illustrates the results of the increasing development of a divergent two-tiered system of care, where more traditional long term care providers care for an increasingly indigent population with more costly and complex needs that threaten to put it out of business.

Offering a unique service - a small, homey setting - it has been at a disadvantage because it is has been too small to pay for itself (the administrator told us they wouldn't break even if they were at full occupancy), is off the beaten track, and its residents live in single rooms and share bathrooms. It cannot compete with other facilities that "have everything" including different levels of care. Caught in a vicious cycle, it has not been able to survive on its own, helped up to a point by a good endowment which contributes ½ its budget. It will soon close.

It has had census problems for many years. The facility has only been filled for short periods of time. Its census has declined to as low as 50 percent. For its private paying residents, the rate is about $2,000. This amount does not go up as needs increase and because of the competition, they are forced to take older, frailer folks with more issues such as more medications and incontinence needs. They also cannot charge a higher private pay rate because that would make them even less competitive. They have several residents on SSI and some on a sliding scale. Costs vary from $80 to $104 per day in any given month. In order to deal with the loss of money, it merged several years ago with an organization that had a nursing home and an adult home. The organization closed its adult home and sent its residents here. Even with the influx of new residents, the facility has only reached 50 percent occupancy. Since the merger it has stopped admitting folks on SSI (in the past 50 percent of its residents were receiving public assistance) although if residents run out of money, the facility keeps them. It has decided to close, build a new adult home, consider other levels of care in addition to the existing nursing home and move its residents to the new campus. The new adult home will also include ALP beds.

This facility provides an interesting contrast to the enriched housing program which uses Medicaid to help get more help for its residents and therefore keep them in the program as long as possible. This facility does not partner with home care agencies, but instead helps residents and families call agencies for home health nurses if they need help. They feel they may not use Medicaid as the other facility does because it may put them at odds with the state in regard to how much care the rate should cover.

Most of the other facilities and programs that serve an impoverished population cannot pay their own way and have survived only through subsidization from operations of the facility's or sponsoring agency's other programs, such as the ALP and outside grants,

Facility 6: Public pay, not-for-profit, suburban enriched housing

Like the enriched housing /ALP, the enriched housing program is a major money loser, (about $50,000 last year), relying on SSI for some of its residents and $1,100 per month from its few private residents. According to the administrator, the actual cost for the program is $47 per day, so the currently configured programs is losing more than $20 a day for the SSI residents and $11 a day for its private pay residents. There are no current plans for elimination of the program. The program is a "mission

driven" service of its sponsoring agency with strong support from its board. The agency's currently strong financial position, sustained by a number of larger programs that generate surplus revenues, has neither produced pressures to close the program nor cut operating costs.

There is, however, no plan to expand the program by acquiring additional apartments and with it, the concomitant increase in the Agency's deficit for this particular program. "If someone were to wave a magic want and raise the SSI payment from $27 to $40, I'd jump on the table and consider expanding." The agency is, however, in the process of developing a joint venture, which would involve a strictly private pay senior housing complex. The two partners have formed a separate for profit corporation and have begun to evaluate sites. This was acknowledged as a "mission distonic" initiative but the surplus could potentially be plowed back into expanding the SSI enriched housing. A more affluent suburban community, with more charitable financial resources and less needs placed on them by low income residents, clearly has more choices.

Facility 7: Public pay, not-for-profit, urban enriched housing

This small enriched housing program admits only those residents who are financially eligible according to Department of Housing and Urban Development (HUD) criteria (income limited to under $940 per month (which is about what SSI level II eligibility is, and savings limited to the Community Medicaid level). The program cannot take any private pay residents, because it would lose the subsidy it receives from the state.

The program loses $40,000 a year when fully occupied. The nursing home which sponsors the program, now eats the $40,000 loss. It provides intensive services, with a nurse and psychiatrist available, and according to the administrator, the state does not begin to cover the costs. Their loss used to be much higher but they saved money by changing food service.

The program's director believes that the program cannot cut any more. She is worried about the ability of the program to continue to give quality care. The program provides its residents with a higher personal needs allowance than it has to. It could cut the personal allowance down to the minimum, but it has felt that the residents need the money. (Annual state rate increases, based upon Social Security cost of living adjustments, are usually divided unequally between facilities and residents, with facilities taking a larger share of the increase. In the past this program has split the adjustment in half, providing residents with a larger increase in their Personal Needs Allowance.)

It manages to care for its residents as they get sicker and need more care by applying for home care for its Medicaid residents. The SSI rate will not cover such care. Indeed, some of their clients have 24 hour home care through Medicaid and 8 hours

through the Lombardi ("nursing home without walls") program that allows Medicaid payment for home care as well. Sometimes family is asked to supply care-giving if needed to keep them in the program.

Facility 8: Public pay, not-for-profit, urban enriched housing ALP

This not-for-profit enriched housing/ALP is the sole provider of enriched housing for the SSI population in the city where it is located. Particularly in terms of the residential units, it compares quite favorably to private market operations and staffing ratios. Although some of the amenities in terms of food preparation and the physical surroundings are lacking, this is not a different basic standard of care.

According to the administrator, the program's costs are $43. Obviously, providing this program to an impoverished population loses money: a United Way grant makes up the difference. This grant subsidizes the resulting deficit of the program at about $175,000 per year.

In the ALP side of the program, the financial numbers are better. For ALP patients the facility receives 50 percent of the Medicaid nursing home rate plus the SSI payment. Home health care agency costs can be high in certain instances but the facility has developed ways to care for residents that save it money. For a resident with a stage three pressure ulcer, for example, it would cost $80 to have the home care agency staff change the dressing. Instead, they can send the resident to a hospital wound clinic, which bills Medicare directly, thus eliminating the $80 charge from the home care agency the program would have to absorb. However, the program will lose the daily payment when the resident is in the hospital.

They do not have any limitations on the admission of people on public entitlement. They currently have one subsidized private pay resident living here. Discharge decisions based upon finances only occur with non-payment. They cannot operate without the SSI check, and in some cases, they have evicted residents. The other constraints to keeping a resident are perceived to be dictated by regulations and facility characteristics rather than the costs of additional staffing to address the increasing needs of residents.

Facility 9: Public pay, for-profit, urban adult home ALP

The adult home we visited has two levels of care: traditional adult home residents and residents who are eligible for the ALP. The ALP helps subsidize the adult home and keeps the facility afloat. According to the administrator, the cost of a resident in the adult home is about $34-35 a day, which means a loss of about $8 a day on each SSI resident. However, there may be some hidden staffing cross subsidies from the ALP that may offset these losses.

The ALP rates, which include Medicaid, is about $95 a day and the cost of a resident in the ALP is about $85 a day. Thus, the facility makes about $10 a day on each ALP resident. The facility also makes money on its home care agency.

The facility admits residents on public support, though they look for people who can pay privately for the adult home (the ALP can only take people on public support). They used to take about 40 percent private - now, with the revenue the ALP brings in, they have reduced that to 30 percent. The ALP has been in existence since 1995 and took only 6-9 months to reach its 98 percent occupancy. They would be satisfied with an 85 percent occupancy in the ALP. If a prospective adult home resident's income is too high for SSI they have sliding scales for rates. Many families supplement the rate. They are very concerned that everyone admitted to the facility is a citizen; they are afraid that immigrants may not be eligible for public funding.

If a resident comes in paying privately, and spends down, the facility helps them apply for public funding and does not discharge them. Private pay families and residents often are upset if told their relative needs more care and that they therefore have to pay more. The facility will try to obtain as much care as possible covered under Medicare. After that, the facility explains to people that they will be able to spend down to the eligibility level for Medicaid and enter the ALP program if medically eligible (i.e., eligible for nursing home care).

Since there is a financial benefit to the facility that receives Medicaid funds through the ALP, it has an incentive to keep an individual in the adult home or the ALP even though he has exhausted his funds. When a resident in the private adult home spends down to a point where he is eligible for Medicaid, he goes to a nursing home.

Facility 10: Public pay, for-profit, exurban adult home for psychiatric and elderly residents

SSI pays for about 90 percent of the residents living in the adult home for the mentally ill and elderly, so this, as others, is by necessity a lean operation. The administrator told us the SSI rate is a disgrace ($50 per day would be reasonable) given New York City pays $50 a night just for shelter for the homeless and State Psychiatric Hospitals can cost as much as $800 a day. The "private pay" here have some limited Social Security and retirement benefits and presumably is not a lot higher than the SSI rate.

There are private rooms allocated to the private pay residents and the rest are semi-private rooms with their own bathrooms. Nevertheless, the facilities and programs look remarkably similar to the private facilities. The administrator told us that they provide more than the required hours per resident for personal care and house keeping, and the resident to staff ratio is about 6.25, which is pretty good. This is supplemented by state supported services provided to the mentally ill that is not available to those facilities with mostly elderly residents. A county program provides

for outings such as ball games, and a psychiatric treatment center provides day programs and transportation for residents who choose to participate. The county Mental Health Center also provides a satellite center at the facility, staffed with social workers, caseworkers and a full time and part-time RN and a part-time psychiatrist. They run groups, do counseling, crisis intervention, and monitoring of the medication of residents. There is also approximately $200-300 per resident per year in Supportive Case Management funds that, at least in theory, can be provided to assist residents with incidental needs such as clothing.

We were told that the facility needs to operate at full capacity to make a go of it, and there are several factors that exacerbate the problems of a lean operation that depends upon an inadequate SSI rate. SSI delays payment a month after one is found eligible, so the facility often has to absorb the cost of the first month, and averages about six to eight new residents a month. These delays also hurt since Medicaid eligibility is often tied to SSI eligibility. Unlike the not for profits, they pay real estate taxes and sales taxes. (7.5 percent) on everything they purchase other than food. They also have a number of loans to pay off for the various renovations they have undertaken in the facility.

Regulation

Facility 1: Private pay, for-profit, suburban unlicensed facility

The administration of this facility would choose registration rather than licensure because the regulations would not allow it to take or retain residents it wants to care for. Regulations would require them to discharge residents who grow more dependent. This facility wants to allow residents to remain, for as long as it can care for the resident. It is their philosophy to allow residents to "age-in." In addition, it was added, "Who wants to be scrutinized?"

However, it is interesting that the nurse who was interviewed believed that the facility should have specific regulations to follow. "Regulations should be uniform and consistent throughout the industry telling facilities what they can handle." Although the nurse did not allow it, the facility pressured her to admit a person she did not feel the facility could care for, when the facility needed to fill beds.

Facility 2: Private pay, for-profit, urban adult home

This facility seems unhappy with both the licensure and inspection system for adult homes. The facility feels that it can rest comfortably on its reputation as a high quality provider without the impediments of licensure. The administrator complained about the survey process. "Inspectors have to find problems. Then it goes on my record. It is a process that only focuses on the negatives. Let them come in and say, "What have you done to improve the quality? If the regulations enhance attractiveness, consumer acceptance, I'm for them. For most facilities, if you give

them the money to do a good job they will do it and overall it will cost 1/3 less." He went on to say that he finds the regulations too confining; he hates the restrictions; the inspectors are too punitive. He also said that he does believe in regulation. This seemed somewhat contradictory. However, it is possible that the issue of how the inspection process plays out is the real issue here as it was with one enriched housing facility (see below).

Facility 3: Private pay, for-profit, urban unlicensed facility

The administrator of this facility told us the facility is trying to get licensed. It believes that if it were licensed, it could have its own home care agency, capture more revenue and the owner can get more profit. This facility believes that the personal care services appear to be more profitable than the "hotel" side of the business.

Facility 4.: Private pay, not-for-profit, urban enriched housing in a hospital integrated delivery system

This facility believes in licensure and would remain licensed no matter what. The administrator believes licensure helps consumers, "If I were a consumer, I would pick a licensed facility. There is more security in oversight." This facility uses the external regulations to avoid a more personalized test of wills between staff and residents and their families; the regulations support the smooth running of the facility.

For this administrator, the issue was not whether to be licensed or not, it was the inconsistency with the oversight of licensed facilities by the state. For example the facility was cited for something that had been ignored by all previous surveyors. Yet, the administrator said "It's always nice to have another set of eyes, even if it is a pain sometimes."

Facility 5: Public pay, not-for-profit, suburban adult home

The administrator of this facility, does not like the registered model. As opposed to other administrators who believed they did not need regulations, this administrator said, "I know what I can hide and I'm licensed - there has to be minimum standards that are enforced." The administrator also talked about problems with surveyors. The inspectors were seen as "paper tigers" who do not look at quality care. "They are not relevant to what you are doing; inspectors should be interested in outcomes, not paper compliance." The administrator, however, did state, as the administrator of the enriched housing did (see below), that, "there is a disconnect between what is required and what we are paid."

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August, 2001

Enclosed is a copy of "Case Studies of Assisted Living in New York: How Well Does the Rhetoric Match the Realities?", a product of the *Assisted Living Project.*

The Assisted Living Project, a three year effort supported by the Fan Fox and Leslie R. Samuels Foundation, provides an objective, systematic description of a rapid, major transformation of care for the frail elderly whose long term implications for New York residents remain unclear. The project included a statewide survey of assisted living and an environmental assessment. For the purposes of the project, assisted living facilities were defined as those facilities that either provide or arrange for assisted living services such as personal care services or help with activities of daily living such as bathing, dressing and toileting. This definition includes licensed adult homes, enriched housing, and assisted living programs and unlicensed facilities that met our definition. In the statewide survey, 470 assisted living facilities in New York State participated in a 163-item telephone survey that achieved an 84 percent response rate. It provides an accurate overview of current operations and dilemmas faced by facilities. The environmental assessment supplies the historical and organizational context propelling the assisted living transformation of care in New York.

The Case Studies explore the nuances and unanticipated complexities of efforts to operationalize the promises of assisted living as a home, a place to age-in place and an environment that allows for the autonomy and flexibility not possible in more "institutional" settings. It also looks at some of the issues related to the financing of assisted living for those using public funding as well as those paying privately and issues related to the staffing of these facilities. For the Case Studies, our research team conducted ten on-site visits to facilities representative of the diversity of assisted living arrangements in New York State. All the facilities we visited were extraordinarily responsive and cooperative during the entire course of our project work.

Our White Paper, which condenses the conclusions of the above research efforts into an action plan, will be released next month.

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