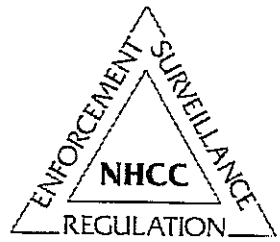
ASSISTED LIVING IN NEW YORK STATE: A SUMMARY OF FINDINGS



NURSING HOME COMMUNITY COALITION OF NEW YORK STATE

THE FOX SCHOOL
of Business and Management
TEMPLE UNIVERSITY

THE HEALTHCARE MANAGEMENT PROGRAM OF TEMPLE UNIVERSITY

THE COALITION OF INSTITUTIONALIZED AGED AND DISABLED

NOVEMBER 2001

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The Fan Fox and Leslie R. Samuels Foundation, Inc.

Acknowledgements

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The conclusions and recommendations presented in this final summary are those of the project team alone (though this research was influenced by the many discussions held with Advisory Group members). The Project (or its products) would not have been possible without them.

We are also grateful for the help of help of the Empire State Association of Adult Homes & Assisted Living Facilities and; the New York Association of Homes and Services for the Aging, who worked with project staff and urged their own members to participate in the study. These groups' assistance was also indispensable to the project's success.

Project Team: Cynthia Rudder, Ph.D., David Barton Smith, Ph.D. and Geoff Lieberman.

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Introduction and Executive Summary

The just-completed (October 2001) Assisted Living Project is an extensive, three-year study of the New York State, assisted living industry. For this study, assisted living facilities were defined as group-housing arrangements that reported to provide or arrange for such personal care services as help with daily-living activities such as bathing, dressing and toileting, etc. Therefore, adult homes, enriched housing, and other facilities providing such services fell within the study's scope.[1]

Introduction

The Project had three components and produced three specific documents[2]:

Environmental Assessment
The assessment compiled data from secondary sources; conducted interviews with more than 100 key informants; reviewed literature, and; composed a narrative to describe the environmental forces that now shape the development of assisted living in New York State. The resulting report, *The Assisted Living Rebellion: Class, Community and the Transformation of Care,* will be published next year in book form.

Facility Surveys
The survey provides a baseline description of assisted living facilities in New York State and their residents. Administrators at 470 qualifying facilities (84 percent of a possible 557) completed the survey. The findings from this component, published in the publication, *A Survey of Assisted Living in New York State: a Summary of Findings* is available and has been distributed to providers, consumers, researchers, and State and Federal policy makers.

In-depth Case Studies of Selected Facilities
Ten, two-day field studies were conducted with a sample of facilities hand-picked to represent different kinds of assisted living facilities (in terms of size, location, type of ownership and type of licensure) that operate in New York State. The resulting report: *Case Studies of Assisted Living in New York: How Well Does the Rhetoric Match the Realities?*, has also been distributed to providers, consumers, researchers, and State and Federal policy makers.

Executive Summary

The findings of The Project, that represent three years of in-depth research, are categorized and summarized into three main areas:

Financing
The study strongly indicates that the need for additional, more-viable, more-flexible financing options will be needed as the aging population grows, especially as the gap between public funding and the cost of an acceptable assisted living, care standard widens. Additional financing is particularly important since the lack of it, more than any

other factor, limits the ability of individuals to safely remain in a facility as they grow more dependent.

The Industry: Consumers and Providers

Findings also indicate the need for facilities to do a better job with both how they represent, and how they deliver services. The promise of assisted living, the ability to give residents autonomy, choice and the right to take risks, is not being fulfilled. Facilities also give a subtle assurance, that is not completely truthful, that seems to guarantee the right to "age-in," stay in the home no matter how sick the resident may get. Residents should have more power over decisions that affect the quality of their lives and facility promotional messages must be clear and accurate.

Policy and Regulation

Greater regulation, through licensing and other government policies, is necessary to more evenly enforce in all facilities, a quality standard in assisted living that provides safe, in-place aging, encourages consumer freedoms, and simplifies consumers' and consumers' families' assisted living provider choices.

A Closer Look at the Findings

This summary distills conclusions from the three previous efforts and suggests how policy makers, facility operators, and residents and their families could best use this information to improve today's New York State, assisted living options.

Financing Today

The study makes clear that, without other financing models, we may have to turn our backs on the progress society made over the last century to ensure a minimum standard of security and care for seniors.

In New York State, the Medicare and Medicaid program assures access to care for the elderly without regard to income to the same hospitals and nursing homes. In assisted living, there are two different kinds of facilities:

Private-pay facilities that exclusively market, admit, and keep only those residents with the ability to pay privately.[3] Forty-eight percent of assisted living facilities in New York are of this type, relying almost exclusively on the private resources of residents and their families for payment.

Public-pay facilities

These primarily accept government dollars and public insurances for services to their residents. About 43 percent of facilities are this type. They rely largely on residents' Supplemental Security Income (SSI), which is available to care for the low-income elderly. Seventy-four percent of residents in all New York State, assisted living facilities have incomes of less than $25,000 (well below the reported average cost of care per year).[4] This means that some residents in private assisted living will exhaust their private resources and be transferred either to public pay assisted living facilities or nursing homes.

In the facilities we investigated that accept SSI-eligible consumers, the inadequacies of SSI payments funds forced these facilities to either reduce service-delivery costs or find additional and/or alternative sources of income. At $27 a day, SSI covers only about half the cost of room, board and personal care. It can cost twice this amount to board a pet in Manhattan.

As the needs of assisted living residents have increased, so have the costs. Many public-pay facilities find it fiscally impossible to cover the costs of increased staffing and services to assure an adequate standard of care and a few operators make the business decision not to try.

Financing in the Future

As the 21st Century progresses, about two-thirds of New York City's elderly will not be able to pay privately for assisted living services. For this group, affordable and quality assisted living is a growing concern. Documents from the assessment component suggest that New York City faces difficult challenges in providing an acceptable standard of assisted living; especially for the elderly indigent.

In New York City, the average, per capita income of people aged 65+ is over $25,000. The average net worth is more than $311,000. If this were the average financial situation for all New Yorkers, it might be presumed that every high-end, private-pay, assisted living facility in the region would be courting their business.

The elderly New York City residents who fall into the low-income category (eligible for Medicare, Medicaid and SSI, too) receive more than $45,000 in annual assistance.[5] This figure is higher than the total per capita income of all but ten of the nation's most affluent counties.

The Downside of a Two-Class System

Nevertheless, the study further indicates an uneven distribution of health care expenses for lower-income people as compared to more affluent consumers. Low-income elderly in New York City typically see two-thirds of their income go toward health care rather than living expenses (this represents almost twice the health care expense as for higher-income populations). This leaves less available income for living expenses for the elderly poor.[6]

While private-pay facilities have been successful at garnering a growing share of those who pay for assisted living expenses (more-affluent consumers), public-pay facilities have had to face the burdensome financial challenge of serving a larger percentage of low-income or indigent patients who also grow more dependent.

Although historically some nursing homes rely on more-affluent patients to garner more profits or surpluses, others, in order to ensure a single, basic standard of acceptable care for all, use this to make up for deficits they incur when they care for the indigent. In many cases, a declining share of private-pay patients translates into increasing financial difficulties for nursing homes and hospitals.

As private assisted living facilities absorb an increasing share of affluent residents who used to be cared for in nursing home, these traditional settings may experience increasing financial difficulties. The growth of a two-class systems of care, as this study suggests could eventually produce higher costs and poorer care quality for all.[7]

Finally, many we spoke with feel that more money for moderate- and low-income persons' care is alone not enough. Many of the most passionate, assisted living advocates argue that more spending-decision power should lie in the hands of the consumers.[8]

Consumer Expectations and Assisted Living Facilities

Advocates for assisted living believe that seniors and other consumers should have the choice to receive care in a place of their own, and remain in place as they grow more dependent (referred to or called aging in-place), and receive individualized care.

Ideal Settings versus Realities

The industry has responded to advocate and consumer demands by making promises to offer their prospects more quality-of-life controls (highlighting the desire to age in-place).

They have made these claims primarily through promotional pieces such as brochures and other advertising.

Yet, during site visits, we found many facilities fell short of such promises and expectations. Often, the facilities remain structured and formalized systems; institutions where assisted living consumers do not have meaningful control over their living or care arrangements.[9] The ability to stay as one becomes more dependent has often been limited. These settings also restricted residents' autonomy, and their abilities to take risks as they would have been free to take in their own homes.

Stumbling Blocks to the Ideals

The study indicates there are many factors that limit residents' ability to age in-place; stay in a facility as their dependencies grow. Some main factors are:

Residents' inability to pay for additional care when needed;

facility policies and procedures that limit in-place aging;

regulations, facility design, and;

residents' unwillingness to live with the disabled.

Crucial Care Issues

We were encouraged to learn that from our site visits that frontline staff knew how to address symptoms that could prevent the need for nursing home placement. Placement in nursing homes, however, sometime occurs because residents exhaust their private assets in private facilities or, because, in public facilities, staff believe residents can't be cared for without additional funding.

Most of the nurses and nurse's aides interviewed proved knowledgeable and skilled in managing and treating (thereby possibly avoiding) the causes (such as incontinence, falling, and cognitive impairments) of premature nursing-home placement.[10]

However, few facilities proved adequately prepared for their residents' growing dependency, or prepared their residents for their neighbors' increasing dependency.

Though frequently ignored, the quality of family-provided care and oversight, regardless of setting, is a critical factor in extending an elderly person's independent-living abilities.

The Consumers' Voices

All providers we spoke with in our site visits saw autonomy, control, and risk-taking as important elderly rights, yet observations suggest that these rights may still elude many residents in assisted living facilities.[12] According to the facility survey, only 61 percent of the unlicensed facilities had formal grievance systems, and only 63 percent had resident or family councils. Many facilities did not allow residents to choose physicians or home health care agencies that were unaffiliated with those same facilities.

While most facilities allowed residents to refuse services the facility considered necessary, the survey showed that little information was given to potential or current residents to help them make informed decisions in general.[13]

Discussions during site visits revealed that residents are often not included in the decision making process. Many residents we met did not have an option about the facility their family member(s) chose for them. Staff told us that many facilities market directly to adult children and bypass the prospective residents altogether. Residents told us they felt their choices for meals, activities and access to the outside community were limited. Our survey indicated that few facilities allowed pets.

The resident councils in the facilities we visited were, for the most part, informational and/or complaint sessions, run by the facility management rather than the residents. Only in two studied locations were council meetings directed by residents.

Although some staff acknowledged during visits that they had to allow residents to take risks, such as providing for a diabetic resident's informed consent to eat sugar, most staff reported they tried to convince residents not to take actions that staff felt unsafe; even when the resident understood the consequences of certain actions. If residents could not be persuaded, the facility would often contact those residents' children and sometimes threaten discharge.

Consumer's Privacy

For the most part, our site visits indicated that only consumers who could afford a private-pay facility had private apartments (that provide a smoother transition from living independently in one's own home). Those that could not afford to pay for a private room or apartment shared rooms with people (many times strangers).

Private-pay facilities do offer shared living as a cost-saving option to those who cannot, or cannot continue, to pay for private-apartments. Most lower-income residents live in licensed adult homes that provide semi-private rooms with a shared bathroom. Only enriched housing programs provide some of the home-like privacy of apartment living to lower-income residents.

Direct-Care Staff Issues

Site visits showed direct-care, staff quality to be the most influential aspect in residents' satisfaction levels; whether the provider is a private- or public-pay facility. We learned that caregivers and residents often forge rich relationships and strong attachments[14]

We met dedicated, caring staff that enjoyed and found satisfaction in their work. "It's like being at home... We are like a family," many told us. Yet, bonds between residents and caregivers were often strained by high turnover, owing to typical low pay, lack of benefits, short staffing, and uncertain hours.

Government Regulations and Assisted Living Facilities

In 1999, New York Governor George Pataki proposed the option of registration instead of licensure for private-pay assisted living facilities. Registration would involve few rules to comply with and little or no State oversight. The proposal did include many disclosure requirements—intended to aid consumers—for registered facilities. Disclosure requirements included such information as: services and fees descriptions; complaint-resolution processes; referral procedures if a contract was terminated, and: admission and discharge criteria.

In June 2001, the New York State Senate passed a bill, introduced by the Chairman of the Senate Aging Committee, that—as with the Governor's proposal—offers the option of registration, rather than licensure for assisted living facilities. It does require extensive disclosure, assessment and discharge-planning policies that are not included in the Governor's proposal, yet still mirrors the Governor's proposal in that it does not provide for regular State oversight.

The Case for Universal Licensure

Before the 1970s, a similar environment of regulatory permissiveness existed in the nursing home industry and major scandals involving various abuses and general poor care were eventually, exposed publicly. The State was forced to tighten regulations, conduct unannounced inspections and stiffen fines for violations. A similar sequence of events may not be imminent in the assisted living industry, but many of those we interviewed expressed concerns about the need to learn from history and not repeat the nursing-home experience in the assisted living world. The study uncovered much support for a more consistent approach to assisted-living-facility regulation through licensure.

Our discussions with residents and family members suggested that it is a very confusing experience to understand the myriad assisted living choices in New York State. There are licensed adult homes, enriched housing and certified, assisted living programs (ALPs) in New York State. Moreover, there are unlicensed facilities that may or may not actually offer true assisted living services, yet they may advertise that they do so.

Many facilities we spoke with expressed a need for a clearer definition of assisted living to help consumers make choices and compare facilities. Legislative proposals not withstanding, some make the argument that most unlicensed, assisted living facilities already meet the definition of either adult homes or enriched housing programs and should be required to be licensed as such under current New York State rules.

Still some unlicensed, assisted living facilities insist that they are just providing rental apartments and an optional package of supportive services that the residents can optionally purchase and therefore should not be licensed either as health or residential facilities.

However, most of the resident contracts, of these facilities, reviewed in the study required residents to give up any rights of tenancy and allow the facility to evict within a month's notice. At least in New York City, tenants have laws that protect them from eviction, and, for many, control rent increases. Even residents in licensed facilities have at least some protections. For the unlicensed, the contracts usually give the resident little recourse. The investigators in this study (and many regulators and consumer groups) are responding to

this dilemma by saying that assisted living providers either cannot or should not be allowed to circumvent both forms of protection for their residents.

Once an individual enters a facility where, contractually, a resident can be discharged if their condition deteriorates, the investigators feel said facility has assumed responsibility for that residents' care and should be licensed just like any other assisted living facility.

Assisted living administrators have mixed opinions about licensure and regulation issues—reflective, perhaps, of sophistication often absent in the public arenas.

Many of the administrators and staff we talked with felt the need to create a more level playing field (e.g. require all facilities to comply with the same rules as each other and to all be inspected by the State on a regular basis.)

Still other administrators indicated that they believed they didn't need licensure because they already provided quality care (though they expressed that other facilities may need such regulation).

The investigators speculate that the first group may have seen this issue within the framework of a competition issue. If the unlicensed became licensed, there would be more competition between facilities. Thus licensing could be used as a comparative marketing tool.[15]

Data also indicated potential quality-of-care issues that seem to call out for licensure policies that require both regulation and outside surveillance/oversight.[16] According to many facility administrators we spoke with, many unlicensed facilities do not have a formal, quality-assurance system.

With no compliances required, census levels may also affect what kinds of residents unlicensed facilities will admit. For example, our visits discovered some instances where low census (population) in unlicensed facilities led the marketing staff to pressure the nursing staff to admit inappropriate residents.

The implication here is that, while some facilities insist that they care for a full range of needs and allow real aging in-place, many of these same facilities have no truly systematic way of reviewing the care needs of patients or of assuring that these needs are met—a pretty basic and widely accepted condition for avoiding substandard care.

More Indications of the Need for ALF Licensure

The following points in this section highlight some of the differences uncovered between licensed and unlicensed facilities that raised investigators' concerns about a universal-licensure need:

Alzheimer's Management:

> Only 57 percent of <u>unlicensed</u> facilities with reported Alzheimer units said their staff had special training, used individualized care plans, or that such units had any special staffing ratios.

In contrast, more than 81 percent of licensed facilities with Alzheimer units had the appropriate arrangements.

Outplacement Arrangements:

Just under half (46.8 percent) of unlicensed facilities reported making any such outplacement arrangements.

Yet, more than 63 percent of licensed facilities reported making outplacement arrangements for their discharged residents.

Medications Management:

Forty percent of unlicensed facilities reported that aides managed medication s for those residents who could not do so for themselves.

Licensed facilities are prohibited against accepting residents who cannot self-administer their medications, or require a Registered Nurse to administer their medications.

Grievance Resolution and Self-Representation:

Sixty-one percent of the unlicensed facilities studied reported a formal grievance procedure in place for residents, and only 63 percent reported any family or resident councils in existence.

By contrast, 97 percent of licensed facilities reported a formalized grievance procedure for their residents, and 92 percent of the licensed reported a resident council in operation.

Adequate Staffing

Staff-member-per-resident ratios in unlicensed facilities are 39 percent of such ratios in licensed counterpart facilities.

While in part this reflects residents who on the whole need less assistance with daily living, it raises concern about whether staffing will keep pace with residents' growing needs in the absence of any monitoring at the regulatory-level.

Administrators and the Licensure Issue

Many of the administrators, nurses and caregivers we spoke with on our visits professed a need to revise and refine the existing, New York State licensure and regulatory requirements. Some saw certain regulations as hindrances to: their facility's support of residents' living choices; safer in-place aging; more residential autonomy, and; more risk-taking freedom.

What the Findings Urge of Policy Makers

The results of our study lead the investigators to urge policymakers to take the following actions:

Require Uniform Licensure
All assisted living facilities should be licensed, and monitored, against a set of minimum standards by the State. Such standards must include, in addition to those related to quality of care, full disclosure regarding the facility's ownership, costs, services, discharge practices, staff qualifications and other critical information that a prospective resident needs in order to make an informed decision when choosing one or another facility. Assisted living facilities should be required to provide private rooms to all residents, regardless of their ability to pay (with the option to share rooms for those who prefer sharing). This should be a requirement of licensure after an appropriate, phase-in period.

Refine Licensure Standards to Reflect the Assisted Living Mission
Regulations should allow residents to age in-place safely, and to have real choices and control over their day-to-day lives and environment. Regulations should ensure the staffing and training are adequate, and that competent residents have the right to take risks as long as the facility makes sure the resident understands these risks. In addition, the regulations should encourage greater resident choice in activities, food, schedules, pets, doctors, home care agencies, and when and where they go in the community. All facilities must be required to have formal grievance procedures and authentic resident-run councils that have real decision-making powers to shape facility operations and policies.

Ensure That There is Adequate Funding to Support the Minimum Standards
Current SSI payments, the only source of funding for many of the State's frail elderly who are dependent on public support, are not sufficient to ensure a minimum standard and/or an adequate supply of care. In order to ensure adequate funding, policy makers should:

Increase State SSI supplements coupled with increased fiscal oversight;

expand the current assisted living programs (ALPs) that supplement SSI with Medicaid dollars;

develop a Medicaid-waiver, demonstration program that supports assisted living for those that may not be eligible for nursing home care; covering such services as administration of medication, transportation and mental health;

develop State partnership programs that provide something closer to universal coverage—through increased incentives—for the purchase of private long-term care insurance coverage;

expand HUD, housing-subsidy programs for the elderly and find other ways to reduce the capital cost of assisted living projects, and;

expand support for a variety of charitable and fraternal groups that provide subsidies for financially drained residents through joint partnerships, incentive

grants and tax policies that encourage them to assume such responsibilities and discourage them from taking and keeping only private-pay residents.

Encourage Self-directed Approaches to Care and Financing
Much effort is needed to support the informal-care system that still serves the vast majority of individuals in need of assisted living services, and; shift control of assisted living support dollars into the hands of assisted living consumers. Further suggestions include:

Expand the existing, enriched housing programs;

expand Medicaid home- and community-based, waiver programs that offer support for consumer-directed care in the home (single-site setting), or in an assisted living facility (congregate-care setting);

encourage self-directed programs similar to those provided to the physically disabled in other states; encourage self-directed programs that give greater choice to those who need assistance;

provide resources and support for informal caregivers, and:

give further, State and City support for elderly residents that have aged in-place in their own homes.

What the Findings Urge of Providers

The results of our study lead the investigators to urge assisted living providers to do the following:

Live the Mission
The mission of all assisted living facilities should be to enhance the quality of life and safe aging in-place for their residents. Important steps that providers can take to achieve this mission are:

Plan for the growing dependency of residents by having necessary processes in place (e.g., quality assurance mechanisms, care planning and risk-taking);

have necessary resources (e.g. sufficient numbers of trained staff);

design (or redesign) the facility to help residents maintain independence and choice as they grow more dependent;

clearly state the mission to prospective residents and families, explaining its spirit, purpose and consequences, and;

prepare current residents for their (and their neighbors') growing frailty.

Provide Full Disclosure
All facilities should provide detailed information regarding the costs, services, discharge criteria, staff training and qualifications, medication policies, and practices for assessing or monitoring health care needs. This material should be available to all who request it. Prospective residents, not just family members should be fully informed.

Make it a Home
Facilities should be able to adapt to the resident rather than expect the resident to have to adapt to the facility. As such, providers should explore ways to give residents the same choices they would have in their own home. Residents should be able to participate in the same activities as they did in their own home—to eat food they have always enjoyed, to choose who they want to eat with, to decide on their own schedules, and on when to get up, when to go to sleep and when to eat. They should be able to choose their own doctors and home care agencies and they should have access to where in the community they want to go; and when. All facilities should establish means for residents to keep pets and have dinner guests.

Empower the Residents: All facilities should establish formal grievance procedures to allow residents to make complaints and receive a timely response. Authentic, resident-run councils are one vehicle for achieving greater resident choice. The development and support of councils that have real decision-making power to shape other policies and facility operations should be encouraged through education, training and real standing in the organizational structure of facilities. Residents should be helped to make their own informed decisions regarding risk-taking. This involves providing education and training to residents and their families, and to all levels of staff, and the establishment of policies and practices that will achieve informed decision-making by residents.

Create a Community
The assisted living movement shares much the same vision as the *resident-centered care movement* in the nursing home industry. Assisted living providers need to join forces with this movement. They both need to learn from each other's experiences. Nonhierarchical and decentralized neighborhood models of care have been developed in some nursing homes with the idea of giving residents and direct-care staff a greater sense of control, and reduce the institutional character of the nursing home environment just as this institutional environment has been designed in at some assisted living facilities.

Give Direct Care Staff the Recognition They Deserve
Pay direct-care staff a living wage and provide them with full benefits. Ensure staff access to additional training and support groups essential to their good performance and career advancement. Enact workplace changes that involve aides and other direct-care staff in decision making about how work is organized. No direct-care provider or staff should ever be refused care themselves when they need it. Providers should ensure through a scholarship program or other mechanisms that any career-oriented, direct-care worker would be welcomed in their facilities regardless of their ability or inability to pay.

What the Findings Urge of Consumers and Their Families

The investigators conclude that consumers have the most important role to play in making the assisted living vision a reality for themselves and their growing ranks. Our recommendations to you are:

Plan It Yourself
Self- or consumer-directed care is the gold standard. We include under this label all the informal ways that families (with the help of neighbors), provide assisted living care, as well as the more formal arrangements that give consumers the resources to direct their own care. It is the best way to ensure that they have the choice to live their own life, take their own risks and age in-place. Yet, self-directed care, whether in the home or in a facility requires planning. Crises can force family members or providers to make choices for residents that should be their own to make. Some precautionary steps must be taken years in advance, such as getting on the waiting list for some care programs, or a purchase of long-term care insurance to ensure that one can afford the assisted living option they want.

Insist on Minimum Standards
Insist that assisted living facilities meet the minimum standards of consumer accountability. Many facilities still do not. A person and their family should be satisfied that the facilities they consider meet the standards below.

The facility should be licensed by the State of New York.

The facility should provide full, complete disclosure of the services residents receive, who will provide them, how residents will pay, and who owns the facility.

The facility should have convincing evidence, endorsed by current residents, that it offers residents a home-like environment, choice and the ability to safely age in-place with help from appropriately trained staff.

The facility has an active resident council, controlled by residents, which help make decisions for the community, and a written, formal grievance procedure that allows residents to make complaints and receive responses in a timely fashion.

The facility should have evidence that, through salary, benefits, tenure, and training opportunities, it values its direct-care staff.

Some consumer groups and provider organizations assist in providing detailed checklists and information on specific facilities. (See the list at the end of this document).

Get Involved!
Participate and become an active supporter of groups that represent consumers of long-term care services and their families. These groups (and their contact information) appear at the end of this report. There is strength in numbers. Assisted living may be simply

absorbed into the existing institutional continuum of care or succeed in truly reorganizing care around its consumers. It may be limited to a privileged few or a right for all. What assisted living does become will determine not just the kind of long term care system we will have but the kind of society.

Consumer Groups

Alzheimer's Association (NYC Chapter)
360 Lexington Avenue, 5th Floor
New York, NY 10017
212-983-0700

Alzheimer's Association (National)
919 North Michigan Avenue
Suite 1100
Chicago IL 60611
800-272-3900
312-335-8700
www.alz.org

AARP
New York State Office
780 Third Avenue, 33rd floor
New York, NY 10017
212-758-1411
www.aarp.org/statepages/ny.html

Coalition of Institutionalized Aged and Disabled (CIAD)
25 West 43rd Street, 3rd Floor
New York, NY 10036
646-366-0867
www.ciadny.org

Consumer Consortium on Assisted Living
P.O. Box 3375
Arlington, VA 22203
(703)-533-8121
www.ccal.org

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(415) 434-3388
(800) 445-8106 (in CA)
www.caregiver.org

Friends and Relatives of Institutionalized Aged (FRIA)
11 John Street
Suite 601
New York, NY 10038
212-732-4455
www.fria.org

Nursing Home Community Coalition of New York State (NHCC)
11 John Street
Suite 601
New York, NY 10038
212-385-0355
www.nhccnys.org

Provider Groups

Assisted Living Federation of America
112000 Waples Mill Road, Suite 150
Fairfax, VA 22030
703-691-8100
www.alfa.org

Empire State Association of Adult Homes & Assisted Living Facilities
646 Plank Road, Suite 207
Clifton Park, NY 12065
518-371-2573
www.ny-assisted -living.org

New York Association of Homes and Services for the Aging
150 State Street, Suite 301
Albany, NY 12207
518-449-2707
www.nyahsa.org

End Notes

[1] "Adult Homes" are adult care facilities that provide long-term residential care to 5 or more adults; "Enriched Housing" is a facility that provides long-term residential care to 5 or more adults, primarily persons 65 or older, in community-integrated settings resembling independent housing units; and "Assisted Living Programs (ALPs) are entities which provide supportive housing and home care services to 5 or more individuals who would otherwise require placement in a nursing facility.

[2] Call the office of the Assisted Living Project for a copy of these documents: 212-385-0355.

[3] Residents or their families who are in "private pay" assisted living must pay out-of-pocket for all the charges that the facility bills them. Private pay facilities do not have provider agreements that would enable them to receive Supplemental Security Income (SSI) and, in some cases, Medicaid payments for indigent residents. In contrast, "public pay" facilities have provider agreements that permit them to directly receive payments for residents from Supplemental Security Income (SSI) and, in some cases, Medicaid. In the telephone survey, 43% of the facilities reported SSI as a source of income and 48% identified the residents' own or family resources as a source of payment.

[4] See Table 7 of *A Survey of Assisted Living in New York State: A Summary of Findings*. For a more detailed description of the financial issues and the disparities from the perspective of providers based on field interviews, tape recorded assisted living marketing and development sessions at national conferences and secondary data sources see: *The Environmental Assessment* (*The Assisted Living Rebellion*) Chapter 1 Growing Old in a City, Chapter 4 Margin and Mission, Chapter 5 Class: Private Pay Assisted Living, and Chapter 6 Community: Public Pay Assisted Living.

[5] Estimates are based on 1998 HCFA AAPCC calculations for New York City's Boroughs, 1998 New York State Health Department Medicaid Data, and income and wealth estimates from the 1998 Federal Reserve survey. See *The Environmental Assessment* "Dollars" section at the end of Chapter 1.

[6] See: *The Environmental Assessment*, Part III. Transforming Care

[7] [7] For a further analysis of the potential impact of assisted living on nursing homes see *The Environmental Assessment* Chapter 4, "The Emergence of the Killer Application." According to a United Hospital Fund report issued in February 2001 61% of New York City's hospitals operated at a loss in 2000, eleven of thirty-six studied by the Fund were jeopardy of closing and another six were also judged at risk. While New York State's nursing homes currently benefit from Medicaid reimbursement closer to private rates than other states, they are unlikely to continue to be insulated from national trends. Use rates in nursing homes for the over 65 population have declined from 6.2% in 1982 to 3.4% in 1999, a decline that in part is attributed the growth of assisted living (see Manton and Gu). (2001) Changes in the prevalence of chronic disability in the United States black and non black population above age 65 from 1982 to 1999, *Proceedings of the National Academy of Sciences*). Five of the top seven largest national nursing home chains, responsible for more than 200,000 residents operated under Chapter 11 bankruptcy protection in 2000 (see Dobson et al. (2000), *Briefing Chartbook on the Effect of the Balanced Budget Act of 1997 and on the Balanced Budget Refinement Act of 1999 on Medicare Payments to Skilled Nursing Facilities* Washington, DC: Lewin Group).

[8] See for example: Assisted Living Federation of America (2000). *Medicaid Consumer Account Program: A New Model for Reimbursement of Home and Community Based Services.* Fairfax, Assisted Living Federation of America.

[9] See Table 6: Admission and Discharge Criteria and Table 7: Payment Issues in telephone survey: *A Survey of Assisted Living in New York State: a Summary of Findings* and pages 4-5 and 16 to 27 in *Case Studies of Assisted Living in New York: How Well Does the Rhetoric Match the Realities?*

[10] See, for example, pages 17- 19 and 22 of *Case Studies.*

[11] See: "Independent Living and Self Organized Care" section of Chapter 1 of *The Environmental Assessment* and Levine (2000) *A Survey of Caregivers in New York City: Findings and Implications for the health Care System.* New York, United Hospital Fund.

[12] See Table 8: Quality of Life Issues in *A Survey* and pages 5 to 9 and 27 to 49 in the *Case Studies*.

[13] See Table 9 in *Survey.*

[14] See pages 9 and 49 to 56 in *Case Studies.*

[15] See pages 12 to 14 and pages 63 to 66 of *Case Studies.*

[16] See Tables 2, 3, 4, 5, 6, and 8 in Survey.