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BOARD AND CARE: A FAILURE IN PUBLIC POLICY

JOINT HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

AND THE

SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

AND THE

SUBCOMMITTEE ON HOUSING AND CONSUMER INTERESTS

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

MARCH 9, 1989

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BOARD AND CARE: A FAILURE IN PUBLIC POLICY

THURSDAY, MARCH 9, 1989

U.S. SENATE, SPECIAL COMMITTEE ON AGING, JOINT WITH SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE AND THE SUBCOMMITTEE ON HOUSING AND CONSUMER INTERESTS, SELECT COMMITTEE ON AGING, U.S. HOUSE OF REPRESENTATIVES,

Washington, DC.

The committees met, pursuant to notice, at 9:30 a.m. in room 628, Dirksen Senate Office Building, Hon. David Pryor (chairman of the Special Committee on Aging), Hon. Claude Pepper (chairman of the Subcommittee on Health and Long-Term Care), and Hon. James J. Florio (chairman of the Subcommittee on Housing and Consumer Interests) presiding.

Present from the Special Committee on Aging: Senators Pryor, Bradley, Shelby, Graham, Kohl, Heinz, Grassley, and Simpson.

Present from the Subcommittee on Health and Long-Term Care and the Subcommittee on Housing and Consumer Interests: Representatives Pepper, Florio, Erdreich, and Regula.

Senate staff present: Portia Porter Mittelman, staff director; Holly Bode, professional staff; John Monahan, investigator; Christine Drayton, chief clerk; Olaf Reistrup, legislative correspondent; and Dan Tuite, printing assistant.

House staff present: Kathleen Gardner Cravedi, staff director; Melanie Modlin, assistant staff director; Peter Reinecki, research director; and Steven Edelstein, counsel, of the Subcommittee on Health and Long-Term Care.

William Benson, staff director; Brian Lindberg, assistant staff director; and David Dean, professional staff member, of the Subcommittee on Housing and Consumer Interests.

OPENING STATEMENT OF SENATOR DAVID PRYOR, CHAIRMAN

The CHAIRMAN. Ladies and gentlemen, the hearing will come to order. On behalf of my colleagues on the Special Committee on Aging, I would like to welcome everyone to this morning's joint hearing on board and care homes. We are pleased to be joined today by our colleagues from House Select Committee on Aging, Subcommittee on Health and Long-Term Care and the Subcommittee on Housing and Consumer Interests.

We are gathered here today to discuss a critical but often overlooked component of this nation's long-term care plan: board and care homes. This hearing is being held to investigate the problems

as well as the attributes of the board and care system. We will explore ways to solve these problems while preserving the good qualities that board and care has to offer.

Board and care homes have traditionally filled the gap between the family home and the nursing home. Unfortunately, that gap is too often filled by providers unsuited and unable to give needed care. Many board and care homes provide care for poor, often mentally ill, disabled individuals who frequently have no family and no place else to go. These residents are among the most vulnerable of our nation's citizens, and far too many are warehoused and forgotten.

More than 41,000 licensed board and care homes are in business today and at least as many unlicensed homes are operating invisibly throughout America. An estimate from 1981 puts the number of board and care residents at anywhere from 500,000 to 1,500,000 citizens. The date and range of that estimate tells you how little we know about board and care.

The Department of Health and Human Services has played an extremely limited role in overseeing board and care facilities. HHS has a total of 118,000 employees on the payroll. Out of all of those 118,000 employees, the amount of resources that HHS is currently devoting to the oversight of board and care consists of one employee who spends approximately one hour each day filing routine reports gathered from the 50 States.

As we will hear today, far too many homes are providing grossly substandard care that endangers the health and well being of their residents. There are a myriad of reasons for why this occurs: a lack of State and Federal involvement, in oversight in regulation, the need for training and education among care providers, and a lack of knowledge in most communities that these facilities, much less these problems, even exist. We in the Congress must explore ways to support those facilities and their residents. Increased licensing efforts, more effective sanctions against substandard homes, strengthened inspections, higher levels of reimbursement to providers, better coordination with other long-term care services in the community and a strong ombudsman presence in the facilities themselves, are but a few of the possible solutions.

Today I look forward to the testimony of the witnesses we have assembled before the committees today. We will focus on the problems in board and care homes. The next time we meet I hope it will be to discuss solutions.

[The prepared statement of Senator Pryor follows:]

OPENING STATEMENT

SENATOR DAVID PRYOR

Chairman, Senate Special Committee on Aging

March 9, 1989 hearing

BOARD AND CARE: A FAILURE IN PUBLIC POLICY

Good morning. On behalf of my colleagues on the Special Committee on Aging, I would like to welcome everyone to this morning's joint hearing on board and care homes. We are pleased to be joined today by our colleagues from the House Select Committee on Aging's Subcommittee on Health and Long-Term Care and the Subcommittee on Housing and Consumer Interests. This is also the Committee's first hearing of the 101st Congress; I hope it is one of many hearings that this Committee will convene to examine the vital concerns and interests of older Americans.

We are gathered here today to discuss a critical, but often overlooked, component of this nation's long-term care system -- the board and care home. They have a vital place on the long-term care continuum in that they can provide elderly and disabled persons with a degree of protective oversight that enables them to maintain a level of independence and autonomy that they would not find in a more restrictive and more costly institutional setting, such as a nursing home. The hearing is being held to investigate the problems as well as the attributes of the board and care system, and to explore ways to solve these problems while preserving the good qualities that board and care has to offer.

What exactly is board and care? "Board and care" is a catch-all term used to describe a wide variety of non-medical residential facilities. These include group homes, foster homes, personal care homes and rest homes. There is a great deal of variance among board and care with regard to size, type of resident, the range of services offered, and the ownership. They usually provide room, meals, assistance with activities such as bathing, dressing, and the taking of medication, and can house anywhere from one to 100 residents. Although traditionally dominated by small "mom and pop" operations and larger establishments sponsored by nonprofit charitable groups, the board and care industry has recently seen the emergence of "assisted living facilities" built by for-profit housing developers. Residents of board and care include the elderly, the physically disabled, deinstitutionalized mentally ill, and the developmentally disabled.

The General Accounting Office (GAO) report on board and care in 6 states, which is being released today, found that board and care homes serving the elderly are usually located in cities, have an average of 23 beds, and are privately operated. Residents of board and care homes typically have physical limitations requiring some oversight, limited incomes (and are frequently Supplemental Security Income, or SSI, recipients), and have often lived in an institution because of a mental disability. They are also unlikely to have friends or relatives visit them on a regular basis, and are

therefore often isolated from the community, and without an advocate to look out for them and protect their rights.

Board and care homes present unique quality problems. They provide care for poor, often mentally ill, disabled individuals who frequently have no place else to go. One of the major problems with operating board and care is that the providers, who are often poor themselves, do not receive enough money from their SSI residents to cover the cost of their care. Individual SSI recipients receive $368.00 per month and couples receive $553.00 per month. Although several states supplement SSI, the average supplement being about $200 per month, it is nonetheless a very small amount of money with which to provide room, meals, supervision, etc. The task of providing adequate care is complicated further by the fact that many of the residents have illnesses or disabilities that demand more care than the board and care operator can afford or is trained to provide.

In 1976, in response to concern about problems in board and care homes, Congress enacted the Keys Amendment to the Social Security Act. It required states to certify to the Department of Health and Human Services (HHS) that all facilities with a large number of SSI recipients as residents met appropriate standards. A 1987 survey of licensed facilities identified about 41,000 licensed homes, with about 563,000 beds serving the elderly, mentally ill and mentally retarded. Of this amount, about 264,000 beds were identified as serving the elderly only. Unfortunately, there are no data available on the number of unlicensed homes. However, it is generally acknowledged that a greater number of homes are unlicensed than licensed. In 1981, HHS estimated that there were anywhere from 500,000 to 1,500,000 residents of board and care facilities. The date and wide range of that estimate illustrate how little we know about board and care.

Problems exist in licensed and unlicensed homes alike; in other words, licensing does not ensure quality care. Licensing requirements vary widely from state to state, and even the very definition of what constitutes a board and care facility differs, so that what may be considered a board and care home in one state (and hence subject to the licensing requirements) is not in another. Further, most inspections focus on the physical plant, with little or no emphasis on the residents and their quality of life. Because states do not aggregate the data gleaned from the inspection reports, the GAO report was limited in its ability to determine the magnitude and type of the violations or the kinds of homes in which the violations frequently occur. However, GAO did find that homes with predominately low-income residents (i.e., SSI recipients) had about twice as many violations on the average as homes with predominately private-pay residents.

A related problem is the lack of strong, efficient enforcement mechanisms for the licensing requirements. The six states that GAO surveyed had the authority to close or revoke the license of a home that was threatening the residents' safety or well-being; in three of the states, this was the only sanction against substandard homes. Although closing a facility is sometimes the only way to handle a chronically substandard home, this all or nothing sanction is usually not invoked --not only is it a time consuming and difficult process, but there are many instances in which it would do more harm than good. In a situation in which the problems could be remedied, or the residents have no place else to go, closing the facility is no solution. Some states have intermediate sanctions, such as fines or receiverships; GAO reports that the states of California and Florida have had limited success with these sanctions, as they are difficult to both invoke and collect.

The Department of Health and Human Services has played a circumscribed role in overseeing board and care facilities. While

the Keys Amendment requires states to establish and enforce board and care standards, it only requires HHS to receive the states' annual certifications concerning compliance. HHS currently allocates only one-eighth of one person's time to checking that the states have sent in their certifications. This amounts to about one hour per day, or five hours per week. Under this policy of very limited follow-up and oversight, a state can report its compliance with Keys even though it may have done little or nothing with respect to monitoring or licensing board and care homes. Furthermore, Keys requires states to report substandard board and care homes to the Social Security Administration so that it can reduce the SSI benefits of any recipient living in such homes. Because this penalizes the residents and not the homes, it acts as a disincentive for states to report deficiencies.

As we will hear today, far too many homes are providing grossly substandard care that endangers the health and well-being of their residents, who are among the most vulnerable and isolated of our citizens. There are a myriad of reasons for why this occurs -- a lack of state and federal involvement in oversight and regulation; the need for training and education among care providers; an absence of knowledge in most communities that these facilities, much less the problems, even exist. We in Congress need to explore ways to support these facilities and their residents, whether through increased licensing efforts and more effective sanctions against substandard homes; strengthened inspections; higher levels of reimbursement to providers; better coordination with other long-term care services in the community; and a stronger ombudsman presence in the facilities themselves are but a few of the possible solutions.

This will require a great commitment -- in terms of time, money, and personnel -- from both the state and federal governments. We are already paying a high price -- in human terms -- for the conditions that exist in too many board and care homes. Despite our budget deficit, I think we should be willing to making quality care in board and care homes a priority, because we can no longer afford the costs exacted by our neglect.

We are fortunate to have with us today a variety of witnesses who will provide testimony on a range of issues surrounding board and care. We are going to hear first from Senator Pepper, who is going to report on the Subcommittee on Long-Term Care and Health's activities on board and care. Senator Pepper will be followed by two panels composed of former residents of some less-than-exemplary homes who will give disturbing accounts of the conditions that existed there; ombudsmen and others who advocate on behalf of residents of board and care; an inspector from a state health department; and an owner and operator of a board and care facility. I am sure that their testimony will open up a great deal of discussion here today, and provide the basis for consideration of these issues in the future. I look forward to their testimony.

With the aging of our population, and the implementation of the provisions of the 1987 nursing home reform legislation regarding screening and appropriate placement of mentally-ill and mentally-retarded nursing home patients, the role of board and care homes will become even more important. The Committee hopes that this hearing will provide a timely opportunity to explore the problems facing board and care residents and providers, and will lead to further discussions of the proper role of the board and care facility in our long-term care continuum, as well as the Federal and State role in oversight and regulation.

The CHAIRMAN. I will yield at this time to Senator John Heinz of Pennsylvania, who has joined with our first witness, the Hon. Claude Pepper, in asking the General Accounting Office for a full report on this issue.

Senator John Heinz.

STATEMENT OF SENATOR JOHN HEINZ

Senator HEINZ. Mr. Chairman, thank you very much.

I am most pleased to be here with you and the committee this morning to examine the conditions in America's board and care homes, which is a rather loosely defined inventory of facilities called home by as many as two million of our frailest and neediest citizens.

As the General Accounting Office report which Congressman Pepper and I requested just over two years ago tells us, some of these homes do provide comfortable quarters and competent care. But in far too many facilities, abuse and despair have replaced board and care and the Federal Government in spite of the Keys Amendment has done nothing about it.

The warning signs of regulatory neglect are the hundreds of cases of mistreatment of residents brought to light by this committee's investigation. To my mind, and these are specific instances to which I refer in the GAO report, when a mentally retarded resident is padlocked to a toilet, that not only constitutes reckless endangerment, but personal degradation. When a resident is beaten with a metal walker, that is not only assault and battery, that is unvarnished brutality. When an elderly woman wastes away to half her body weight from lack of proper nutrition, that is not just gross incompetence, it is unbelievable neglect. And when an older man dies in a home because hospitalization would cut off his SSI check to the provider, that is not only larceny, it is murder.

For the past nine years, Congress has focused its attention on access to quality, affordable care in hospitals, home health agencies, and nursing homes. While we were busy certifying and regulating elsewhere, the board and care industry was burgeoning out of sight, out of mind, and we now know, out of control. Congress has only the 1976 Keys Amendment as a regulatory stick. And the GAO report and the committee investigation tell us that the Keys Amendment is not enough.

We find ourselves today trying to lasso and brand a murky industry. But at least our challenge is clear. In the next few weeks, I hope to introduce legislation to strengthen State inspection efforts with Federal financial assistance and beyond that to establish standards for structural safety and sanitation, for adequate nutrition and proper personal care. We need a residents' bill of rights. We need credible Federal sanctions to enforce these standards, access for ombudsmen and many of the things that Senator Pryor mentioned.

Mr. Chairman, let me just say in conclusion, just three years ago this committee turned the Congress around on the need for nursing home reforms. I am confident we can do the same job of consciousness raising and reform here today. Thank you.

[The prepared statement of Senator Heinz along with the prepared statements of Senators Glenn, Breaux, Kohl, Grassley, and Warner follows:]

NEWS FROM
SENATOR JOHN HEINZ
SPECIAL COMMITTEE ON AGING
Senate Hart 628 Washington, D.C. 20510-6400 (202) 224-1467

OPENING STATEMENT OF SENATOR JOHN HEINZ (R-PA)
BOARD AND CARE HOMES: FAILURE IN PUBLIC POLICY
9 MARCH 1989

Mr. Chairman, good morning. I am pleased to be here with you this morning to examine conditions in America's board and care homes--that rather loosely defined inventory of facilities called "home" by as many as 2 million of our frailest, neediest citizens.

As the General Accounting Office report, which Congressman Pepper and I requested, tells us, some of these homes do provide comfortable quarters and competent care. But in far too many facilities, abuse and despair replace board and care-and the Federal government has done nothing about it.

The warning signs of regulatory neglect are the hundreds of cases of mistreatment of residents brought to light by this Committee's investigation. To my mind, when a mentally retarded resident is padlocked to a toilet, that constitutes reckless endangerment. When a resident is beaten with a metal walker--that's assault and battery. When an elderly woman wastes away to half her body weight from lack of proper nutrition, that's gross neglect. And when an older man dies in a home because hospitalization would cut off his SSI check to the provider--that's murder.

For the past nine years, Congress has focused its attentions on access to quality, affordable care in hospitals, home health agencies and nursing homes. While we were busy certifying and regulating elsewhere, the board and care industry was burgeoning out of sight, out of mind--and out of control. Congress has only the 1976 Keys Amendment as a regulatory stick. And the GAO report and the Committee investigation tells us that the Keys Amendment isn't enough.

We find ourselves today trying to lasso and brand a murky industry. But at least our challenge is clear. In the next few weeks, I plan to introduce legislation to strengthen state inspection efforts with Federal financial assistance. Beyond that we need standards for structural safety and sanitation, for adequate nutrition and proper personal care. We need a residents' bill of rights. And we need credible federal sanctions to enforce these standards.

Mr. Chairman, just three years ago this Committee turned the Congress around on the need for nursing home reforms. I am confident we can do the same job of consciousness raising and reform here.

STATEMENT OF SENATOR JOHN GLENN

at a joint hearing on

BOARD AND CARE: A FAILURE IN PUBLIC POLICY

before the

U.S. SENATE SPECIAL COMMITTEE ON AGING
and the
U.S. HOUSE OF REPRESENTATIVES SELECT COMMITTEE ON AGING
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE
SUBCOMMITTEE ON HOUSING AND CONSUMER INTERESTS

9:30 A.M. Room 628 Dirksen Building
Thursday, March 9, 1989 Washington, D.C. 20510

Mr. Chairmen, I commend you for holding this hearing to highlight the problems associated with board and care facilities. I hope that the information provided today will prompt both the Federal and State governments to get serious about ensuring a clean and safe living environment for many of our nation's elderly and mentally-impaired citizens.

For many people, board and care homes are the most appropriate housing alternative. As our population ages, we will need more community-based residences for persons who cannot remain alone but who do not need institutional nursing home care. Because of the importance of board and care homes we must act promptly to correct the current situation in which we find thousands of people living in group homes where residents are receiving inadequate food and care, are being physically and mentally abused, and are dying due to lack of appropriate medical attention.

I share the concerns of my colleagues about the abuses we have found in board and care homes and which will be described by many of today's witnesses. I would particularly like to acknowledge and thank one witness, Ms. Melva Colegrove, who is here from the Ohio Department of Health to describe the terrible conditions she has found during her investigations of board and care facilities. And I hope to have an opportunity to ask her about the actions being taken by Governor Richard Celeste and others in Ohio to license board and care facilities and to increase the State payment for Supplemental Security Income (SSI) recipients.

I am also aware that there are good providers who are struggling to provide high-quality care to residents who are unable to pay the full costs of their care. I welcome one such person, Ms. Pam Hinckley from Cleveland, Ohio, and look forward to her testimony.

The information we receive from today's witnesses, along with the reports of the United States General Accounting Office, our two Aging Committees and others, will be helpful in determining the extent of the board and care problem and in recommending options to ensure the provision of high-quality care in community residential facilities. I thank you all for your participation in this hearing, "Board and Care: A Failure in Public Policy."

STATEMENT OF SENATOR JOHN BREAUX

SENATE SPECIAL COMMITTEE ON AGING

BOARD AND CARE HOMES: FAILURE IN PUBLIC POLICY

Before getting started, I would like to thank our new Chairman, Senator David Pryor as well as Congressman Claude Pepper, the Chairman of the House Aging Committee's Subcommittee on Long Term Care and Congressman Jim Florio, the Chairman of the Subcommittee on Housing and Consumer Interests for putting together this hearing on board and care homes. I would also express my thanks to Senator Heinz for his role in shedding some light on conditions in these facilities and the atmosphere in which they operate.

The General Accounting Office's report gives us a series of horror stories that are almost too much to believe. We are presented with board and care home operators who punish their residents by putting them on a diet of bread and water or abusing them with cattle prods. Residents have been left lying for hours and days at a time in their own wastes, they have been sexually abused, had their money stolen, been tied up and filled with mind-altering drugs to keep them quiet and they have been starved, all by the very same people that they are relying on to protect them. This should not be allowed to happen. It is a disgrace.

I recognize that these are anecdotes and that not all board and care operations are bad. We are all constrained by the limited options for long term care that are available. Residents of board and care facilities often have no other source of income than their SSI check. In states that do not provide a supplement to SSI, that's $354 a month at the most. Private operators of even the most reputable board and care facilities are thwarted by the low level of payment that they can expect from their clients.

In an ideal world we would shut down every substandard board and care home throughout the country before tonight is out. Unfortunately, we have to acknowledge the grim reality

that the residents of these homes are there because they just don't have anywhere else to go. If we shut down a home, we can't be sure that we will have a place to send the residents who then have no roof over their heads, no place to sleep or eat and no one to help them manage with simple activities like bathing and taking their heart pills or insulin on time.

The efforts that have been made at the state and federal level have not been good enough. Congress has enacted nursing home and home care guidelines, but has not done the same at the board and care level. Meanwhile, provisions in the Omnibus Budget Reconciliation Act of 1987 (OBRA), which call for screening of nursing home residents, promise to increase the number of people looking for the services that board and care homes can provide.

State governments have not chosen to arm themselves with effective methods or adequate resources for enforcing their own standards for board and care homes. In many states, including my own Louisiana, the only option that states have is to shut down a home. Some states have instituted a system of fines, which give them an intermediate tool for enforcing their standards. Few, however, have enough people going out into the field to inspect licensed homes or uncover unlicensed homes.

The federal government has not armed itself properly either. The only penalty that the Department of Health and Human Services can inflict is to withhold part of the SSI check that goes to board and care home residents. This only hurts the individual SSI recipient. It does not help the situation. States have no incentive to report that their board and care homes are out of compliance.

The Keys Amendment to the Social Security Act, enacted in 1976, outlines the minimal federal role that does exist in the regulation of board and care homes. States are required to establish regulations, but there are no minimum guidelines. States are required to certify to the Secretary of the Department of Health and Human Services that they are in compliance with their own regulations. Neither the states

nor HHS take their roles under the Keys Amendment seriously. The GAO tells us that in 1988 the Department of Heath and Human Services received certification from only 25 states. GAO also tells us that officials from two states that are certified freely acknowledge that they have thousands of homes that should fall under the state regulations mandated by the Keys Amendment, but are not regulated in any way, shape or form. HHS apparently is not bothered by this because they devote only one-eighth of one employee's time to seeing that the states have sent in their certifications.

I am glad that we are here today to start exploring some causes and possible courses of action. There are too many easily-found examples of abuse and neglect in board and care facilities for nothing to be done. Meanwhile, though, we need to be careful not to price those elderly, mentally ill and mentally retarded people who are dependent on SSI as a sole source of income out of the board and care market.

I am looking forward to an educational series of hearings on what our options are and would like to thank today's witnesses for coming forward to share their views and experiences with us.

STATEMENT OF SENATOR KOHL

Mr. Chairman, I certainly want to join you and our colleagues from the House and the Senate in paying tribute to Claude Pepper. I do, however, want to dissent from the tone of some of the tributes we have heard in the past. It seems to me that all too often people comment on how remarkable it is that Claude Pepper remains an active force while being 88 years years old. In truth, I don't find that very remarkable. It may be unusual -- most people decide to give up this sort of nonsense a lot sooner than that -- but to link his age and his continued contributions to American society seems to suggest that older people really can't do all that much. And they can. Claude Pepper is not the exception who proves that rule; he is the rule.

So I don't find Mr. Pepper's age to be worthy of comment. Instead, I find his consistency and commitment worthy of admiration.

Prior to this hearing I did a little reading about his background and what struck me most was something that Congressman Pepper wrote a few year ago. Let me share it with you. He said that he entered public life because his experiences, growing up in the destitute South convinced him "that life for human beings should, and could, be much better than it was. What worthier purpose could government serve than to make life a bit happier and a lot less arduous for its people?"

That was the question that Claude Pepper asked. His career is the answer.

The hearing we are having today is simply a continuation of that answer, of that career. Once again, Claude Pepper is calling to our attention an injustice, a flaw, a problem. We have been trying to deal with the problem of inadequate care in Residential facilities for some time. We have taken some steps. But apparently we have not gone far enough. The evidence we will hear today is both distressing and depressing. But during the course of these hearings we will also hear that there is some action we might take to address this problem. I'm sure that Claude Pepper will make sure that we do more than consider solutions -- he'll do everything he needs to to make sure we adopt them. I look forward both to his testimony today and his continued involvement in dealing with this problem in the years to come.

STATEMENT OF SENATOR CHARLES E. GRASSLEY AT A HEARING OF THE SPECIAL COMMITTEE ON AGING ON THE TOPIC OF BOARD AND CARE HOMES, THURSDAY, MARCH 9, 1989.

THANK YOU, MR. CHAIRMAN.

I WANT TO WELCOME SENATOR PEPPER AS AN HONORARY MEMBER OF THE SENATE COMMITTEE ON AGING AND TO TELL YOU THAT I APPLAUD YOUR DECISION TO HONOR HIM IN THIS WAY.

IT'S CERTAINLY FITTING THAT WE WELCOME HIM AS AN HONORARY MEMBER. SENATOR PEPPER WAS A CHARTER MEMBER OF THE HOUSE AGING COMMITTEE, AS WAS I, AND SERVING FOR SEVERAL YEARS WITH HIM ON THE AGING COMMITTEE IS CERTAINLY ONE OF THE HIGHLIGHTS OF MY OWN CAREER IN THE CONGRESS. WERE IT NOT FOR THE TWISTS OF ELECTORAL FORTUNE, SENATOR PEPPER MIGHT WELL NOW STILL BE IN THE U.S. SENATE AND THE SENIOR MEMBER OF THIS COMMITTEE.

SENATOR PEPPER HAS WELL-EARNED YOUR PRAISE BY MANY YEARS OF CONSISTENT EFFORT TO IMPROVE THE LOT OF OLDER AMERICANS. IN FACT, IT IS ENTIRELY APPROPRIATE THAT YOU CHOOSE THIS FIRST HEARING OF YOUR CHAIRMANSHIP TO HONOR SENATOR PEPPER AND TO CONSIDER BOARD AND CARE HOMES.

BECAUSE, AS SOME OF US REMEMBER, SENATOR PEPPER WAS CONCERNED ABOUT BOARD AND CARE HOMES, AND HAD INTRODUCED LEGISLATION ON BOARD AND CARE HOMES, AS LONG AGO AS 1977.

ON THE MATTER OF BOARD AND CARE HOMES, MR. CHAIRMAN, I THINK IT IS APPROPRIATE THAT THIS COMMITTEE REVIEW THE ISSUES THAT THEY RAISE.

AFTER A FLURRY OF INTEREST AND ACTIVITY IN THE CONGRESS ON THIS SUBJECT IN THE LATE SEVENTIES AND EARLY EIGHTIES, ATTENTION TO IT, AT THE NATIONAL LEVEL AT ANY RATE, SEEMS TO HAVE WANED.

THE DEPARTMENT OF HEALTH AND HUMAN SERVICES HAD A BOARD AND CARE INITIATIVE IN THE EARLY EIGHTIES, BUT IT IS HARD TO POINT TO ANY DISTINCT ACCOMPLISHMENTS FROM THAT INITIATIVE.

ACCORDING TO THE GAO, OVERSIGHT OF BOARD AND CARE HOMES BY STATE GOVERNMENTS SEEMS TO BE PARTIAL AT BEST.

PART OF THE PROBLEM MAY BE CAUSED BY THE FACT THAT A CONSENSUS SEEMS TO AGREE THAT THE MAIN ENFORCEMENT POWER

AVAILABLE AT THE FEDERAL LEVEL IS UNUSABLE. THIS IS THE KEYS AMENDMENT, SECTION 1616(E) OF THE SOCIAL SECURITY ACT, WHICH PASSED IN 1976. IT IS NOT ENFORCEABLE BECAUSE IT WOULD PUNISH SUPPLEMENTAL SECURITY INCOME RECIPIENTS RATHER THAN THE MANAGEMENT OF BOARD AND CARE HOMES. FEW OF US WOULD HAVE ANY TASTE FOR THAT.

IN ANY CASE, MR. CHAIRMAN, I LOOK FORWARD TO THE TESTIMONY OF OUR WITNESSES TODAY, AND TO THE FURTHER ACTIVITIES OF THIS COMMITTEE ON THIS SUBJECT.

STATEMENT OF SENATOR JOHN WARNER
March 9, 1989

SENATE SPECIAL COMMITTEE ON AGING
HOUSE SELECT COMMITTEE ON AGING SUBCOMMITTEES
ON
HEALTH AND LONG TERM CARE
AND
HOUSING AND CONSUMER INTERESTS

- - - - - -

Joint Hearing on Conditions In The Nation's
BOARD AND CARE Residential Facilities

- - - - - -

CHAIRMAN PRYOR, SENATOR HEINZ, CHAIRMAN PEPPER, AND CHAIRMAN FLORIO, IT IS A HIGH PRIVILEGE, AND ONE FOR WHICH I AM DEEPLY GRATEFUL, TO AGAIN ASSOCIATE, AFTER AN ABSENCE OF TWO YEARS, WITH THE CONGRESSIONAL LEADERSHIP ON POLICY AFFECTING OLDER AMERICANS.

IT IS PARTICULARLY FITTING THAT CHAIRMAN PRYOR HAS CHOSEN TO INITIATE THIS MORNING'S HEARING WITH A TRIBUTE TO OUR REVERED COLLEAGUE, SENATOR CLAUDE PEPPER, A MAN WHOSE ADVOCACY FOR OLDER AMERICANS IS NOW LEGENDARY. I JOIN IN THE SALUTE TO CHAIRMAN PEPPER AND WISH HIM LONG YEARS OF CONTINUED SERVICE.

THE BUSINESS OF OUR JOINT MEETING IS ONE WHICH CONCERNS ME GREATLY: THE STATE OF CONDITIONS IN THE NATION'S BOARD AND CARE RESIDENTIAL FACILITIES. WE OWE A DEBT OF GRATITUDE TO OUR SENATE RANKING MEMBER, SENATOR HEINZ, AND TO CHAIRMAN PEPPER FOR HAVING REQUESTED THE GENERAL ACCOUNTING OFFICE (GAO) REPORT DURING THE LAST CONGRESS. TODAY WE RELEASE ITS PUBLICATION AND GET OUR OWN ASSESSMENT UNDERWAY.

AMONG THE SIX STATES EXAMINED BY GAO WAS THE COMMONWEALTH OF VIRGINIA. WITH 18,081 BEDS IN 404 LICENSED HOMES FOR ADULTS, MY STATE HAD MUCH TO OFFER IN THE WAY OF DATA AND STANDARDS OF CARE. I AM PLEASED THAT VIRGINIA LENT ITS FULL COOPERATION AND THAT THE GAO REPORT HAS BEEN COMMENDED BY COMMISSIONER LARRY JACKSON OF THE VIRGINIA DEPARTMENT OF SOCIAL SERVICES.

I WOULD ALSO LIKE TO ACKNOWLEDGE THAT ONE OF THE NATION'S PRINCIPAL BOARD AND CARE PROVIDER ORGANIZATIONS IS CURRENTLY BASED IN RICHMOND, VIRGINIA: THE NATIONAL ASSOCIATION OF RESIDENTIAL CARE FACILITIES. ALTHOUGH NEITHER THIS ORGANIZATION NOR ANY OTHER PROVIDER GROUP IS TESTIFYING TODAY, I UNDERSTAND

THAT THEY WILL BE EXTENDED AN INVITATION AT A LATER SUPPLEMENTAL HEARING, PERHAPS WHEN WE BEGIN OUR CONSIDERATION OF SPECIFIC LEGISLATIVE RECOMMENDATIONS. THE ASSOCIATION HAS MADE A SIGNIFICANT CONTRIBUTION, NONETHELESS, IN THAT THE RESULTS OF ITS OWN 1987 NATIONAL BOARD AND CARE SURVEY HAVE BEEN SUBSTANTIALLY UTILIZED IN THE GAO REPORT.

THROUGHOUT THE MATERIALS WHICH HAVE BEEN PREPARED FOR THIS HEARING, IT IS CLEAR THAT IN SPITE OF A LARGE NUMBER OF WELL MANAGED BOARD AND CARE FACILITIES, THERE ARE HORROR STORIES TAKING PLACE OF RESIDENTIAL ABUSE AND DEPRIVATION. SOME OF THOSE WILL BE SHARED WITH US.

WHAT ALSO SEEMS CLEAR IS THAT NO SINGLE ENTITY IS TO BLAME. DEINSTITUTIONALIZATION OF THE MENTALLY ILL AND MENTALLY RETARDED, A POLICY WITH PRAISEWORTHY GOALS, HAS TAKEN PLACE BEFORE COMMUNITIES HAVE HAD THE MEANS TO PROVIDE PROPER CARE.

THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES HAS NOT FOLLOWED THROUGH ON ITS 1981 PROMISE TO SEND THE CONGRESS NEW BOARD AND CARE LEGISLATION. NOR HAVE THE STATES DEVOTED THEIR RESOURCES TO STRICTER LICENSING, CERTIFICATION, AND SANCTIONING. IN ADDITION, I BELIEVE THE SOCIAL SECURITY ADMINISTRATION SHOULD IMMEDIATELY CRACK DOWN ON BOARD AND CARE ABUSE OF BENEFICIARY PAYMENTS.

CHAIRMAN PRYOR, SENATOR HEINZ, DISTINGUISHED CHAIRMEN FROM THE HOUSE, I REALIZE THERE IS A FULL AGENDA BEFORE THE JOINT MEETING AND THAT TIME IS LIMITED. TIME MAY ALSO BE LIMITED FOR THE LONG SUFFERING AND NEGLECTED RESIDENTS OF ILL-MANAGED AND NON-POLICED BOARD AND CARE HOMES. LET'S GET THE WORD OUT ON SUCH CONDITIONS AND DELIVER THEM A MEASURE OF RELIEF.

The CHAIRMAN. Thank you, Senator Heinz. Chairing the Subcommittee on Housing and Consumer Interests from the House of Representatives is the Honorable James Florio. Congressman Florio, we look forward to hearing from you at this time.

STATEMENT OF CONGRESSMAN JIM FLORIO

Mr. FLORIO. Thank you very much, Mr. Chairman.

I am pleased to join with my distinguished colleagues on the House Select Committee on Aging as well as the Senate Special Committee on Aging in convening this extremely important meeting here today.

Mr. Chairman, as I review the findings of the GAO report, Mr. Pepper's report, and an investigation that my subcommittee conducted in my own State of New Jersey, I was struck by the fact that we allow things to happen in board and care facilities that we do not allow to happen elsewhere.

To begin with, under the Older Americans Act we provide meals to older adults in congregate settings and in their homes and those meals must meet certain standards of nutritional value. Yet in too many board and care homes meals are not monitored at all. My staff and Mr. Pepper's staff have seen first-hand the stale, starch-ridden, unnutritious, and simply unappealing meals that are literally thrown in front of residents. A meal consisting of either a scoop of spaghetti or a bowl of puffed rice for dinner along with an old donut and a cup of coffee would not be tolerated at a seniors' meal site, a nursing home, or a Section 202 project, so why is it tolerated in this type of a setting?

We close down restaurants here in Washington that have filthy or non-functional restrooms, but we allow board and care homes to exist with bathroom facilities that would make many of us ill. Our staffs have visited smelly, unsanitary outhouse-like facilities with unlockable doors and no toilet paper, and toilets available to both men and women that do not have locks.

We would not tolerate a bank that withheld funds that were rightfully the customers'. In a board and care facility it's a different story; we have allowed management to deny residents their personal needs allowance, abscond with their home energy assistance payments, and coerce other monies from frail residents. Facility operators who are named by the Social Security Administration as representative payee for their residents have complete control over their finances, and in some cases rip them off.

To put this in perspective, on average it costs about $11 per day to board a 70-pound dog in New Jersey, and that is for only one meal a day, water, and a place to run. Astonishingly, in New Jersey board and care residents who are dependent upon SSI receive a low of $11.30 to a high of just under $16 for their lodging, meals, and care in a board and care facility. And in States that do not supplement the Federal SSI amount, the daily rates are even lower. This is the kind of respect that we show fellow Americans who happen to be less fortunate, and far more vulnerable than most of us.

Every State, including my home State of New Jersey, has some facilities run by caring people. The fact is that if they wish to serve

low-income disabled Americans, the SSI rates make it pretty tough if not close to impossible to do a good job. The good guys in this business are being devastated by those who engage in the abuses we will hear about today. We need to keep those caring people in the business.

Mr. Chairman, I have several submissions I would like to put into the record. Thank you.

The CHAIRMAN. Without objection the submissions will be placed at the appropriate part in the record.

[The prepared statement and submissions referred to by Congressman Jim Florio and the prepared statements of Representatives Oakar, Bentley, Regula, and Borski follow:]

Congressman
Jim Florio

New Jersey's First
Congressional District

STATEMENT OF
CONGRESSMAN JAMES J. FLORIO
ACTING CHAIRMAN
SUBCOMMITTEE ON HOUSING AND CONSUMER INTERESTS
HOUSE SELECT COMMITTEE ON AGING
JOINT HEARING WITH THE
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE
SELECT COMMITTEE ON AGING
AND THE
SENATE SPECIAL COMMITTEE ON AGING
BOARD AND CARE HOMES IN AMERICA: A FAILURE IN PUBLIC POLICY
MARCH 9, 1989

Good morning. I am pleased to join my distinguished colleagues of the House Select Committee on Aging and of the Special Committee on Aging in convening this extremely important hearing.

Before I comment on the crisis that faces us in the board and care industry, I too wish to take this opportunity to praise our first witness today, the former Chairman of the House Aging Committee and current Chairman of the Subcommittee on Health and Long-Term Care, Senator Claude Pepper. I have had the honor of serving with Claude Pepper for 10 years on the Aging Committee and he is unquestionably the strongest — and best known — advocate in Congress for improving the quality of life for older Americans. I am delighted that the Members of the Senate Aging Committee concur with this as evidenced by today's special recognition of Senator Pepper. We could not have a better lead-off witness on any topic affecting the elderly and certainly not for today's subject.

As the Acting Chairman of the Subcommittee on Housing and Consumer Interests, I am acutely aware of the importance of board and care facilities as a form of housing. As we know, board and care facilities are difficult to label. They bring into play housing, long-term care, health care, supportive services, and income security issues. Residents of board and care facilities are looking for a roof over their heads, but they also need a supportive environment. We have found that they are often frail elderly individuals with mental impairments or physical disabilities. And although there are many victims of all ages in bad board and care homes, we - the Aging Committees - have an important role in demanding improvements in this industry.

Mr. Chairman, as I reviewed the findings of the GOA report, Mr. Pepper's report, and the investigation that my subcommittee staff conducted in New Jersey, I was struck by the fact that we allow things to happen in board and care facilities that we do not allow to happen elsewhere.

To begin, under the Older Americans Act we provide meals to older adults in congregate settings and in their homes, and those meals must meet certain standards of nutritional value. Yet, in too many board and care homes meals are not monitored. My staff and Mr. Pepper's staff have seen first hand the stale, starch-ridden, unnutritious, and simply unappealing meals that are literally thrown in front of residents. A meal consisting of either a scoop of spaghetti or a bowl of puffed rice for dinner along with an old donut and a cup of coffee would not be tolerated at a seniors' meal site, a nursing home, or a Section 202 project, so why is tolerated in this setting?

We close down resturants here in Washington that have filthy or non-functional restroooms, but we allow board and care homes to exist with bathroom facilities that would make many of us ill. Our staffs have visited unsanitary facilities that smell and have unlockable doors and no toilet paper. Imagine toilets available to both men and women that do not have locks.

We would not tolerate a bank that withheld funds that were rightfully the customer's. In a board and care facility it's a different story; we have allowed management to deny residents their personal needs allowance, abscond with their home energy assistance payments, and coerce other monies from frail residents. Facility operators who are named by the Social Security Administration as representative payee over their residents have complete control over their finances, and in some cases steal their benefits.

To put this in perspective, on average it costs about $11 per day to board a 70-pound dog in New Jersey — and that is for only one meal a day, water, and a place to run. Astonishingly, New Jersey board and care residents dependent upon SSI receive a low of $11.30 to a high of just under $16 for their lodging, meals, and care in a board and care home. And in states that do not supplement the Federal SSI amount, the daily rates are even lower. This is the kind of respect that we show fellow Americans who happen to be less fortunate, and far more vulnerable than we.

We need to face the hard fact that just because we don't see board and care residents on the grates of our cities, that doesn't mean that they have a decent place to live. While they are not homeless, they are often prisoners of their own room, too often trapped by psychotropic drugs, staff that care little for their welfare, or who are simply incapable of providing adequate

support. Personal effects are not safe, a resident may be robbed while he or she is eating dinner or in the hospital for a few days. Their few items of clothing may be sent to be laundered never to return - with no effective recourse.

When one looks at each of these examples of "abuses", one might say that "things are not too bad - at least they are not out in the snow." But that is the easy way out. For starters, it seems that many board and care residents are just a step away from homelessness. Forty years ago the Federal Government committed itself to providing a decent living environment for every American. We in Congress cannot and should not stand outside the board and care facilities of this Nation and pretend that the terrible conditions that many of those residents face are not our responsibility.

Every State, including my home State of New Jersey, has some fine facilities run by caring people. The fact is that if they wish to serve low-income disabled Americans, the SSI rate makes it pretty tough if not close to impossible. The good guys in this business are being devastated by the those who engage in the abuses we will hear about today. We need to keep those caring people in this business.

As the testimony and reports we receive today will show, our current role has proven to be completely insufficient. We simply are not doing anywhere near enough at the Federal level to protect these vulnerable citizens.

I am pleased that the GAO report presents a positive view of New Jersey's board and care quality and regulatory structure, especially compared to other States in their study. Nonetheless, those of us from New Jersey cannot be complacent because our State continues to have serious quality problems.

I am delighted that one of today's witnesses is one of New Jersey's outstanding advocates and experts on board and care. David Lazarus of the Community Health Law Project will tell us about the problems in New Jersey, the comments of the GAO notwithstanding, he will share his experiences on what we need to do to improve this unacceptable situation.

We are here to learn a great deal and then to seek responsible ways to address these problems. Our witnesses will offer possible approaches to solving some of the problems. Allow me, however, to a suggest a few quick points which I believe would contribute to improving the lives of board and care residents:

* Clearly, the Federal SSI rate must be increased, eligibility criteria improved, and administration strengthened.

* We desperately need a system of community-based long-term care services. I have introduced with Henry Waxman, H.R. 854, the Medicaid Community and Facility Habilitation Services Amendments of 1989 -- which is a companion to Senator Chafee's bill. It may be useful as a model for providing rehabilitative and family-like settings. Large 150 bed institutional-style facilities are not going to do the job.

* The rights of residents and ways to improve their access to advocacy services must be enhanced. The law governing the Older Americans Act's Ombudsman program was improved recently, but without a semblance of decent funding, those provisions may be essentially meaningless. Legal services programs also need more support.

* Capital funds must become more available for acquisition, construction, and rehabilitation of appropriate facilities.

* We need to ensure that all States have laws on the books to protect board and care residents and to make sure those laws have teeth.

* The operators and staff of these facilities must be educated and trained -- they make or break the facility, and sometimes the residents. There are many operators who desperately want to do a good job but without adequate training they just don't have the tools.

* Federal, State, and local barriers to providing services on-site at board and care facilities must come down, whether those barriers are statutory or attitudinal.

Finally, Chairmen Pryor and Pepper, I would like to offer several items for the record.

* First, I have a subcommittee report containing the observations of my staff from visits they made to New Jersey board and care homes.

* Second, I have a chronology that I asked CRS to prepare of Federal activities related to board and care. It contains 29 entries dating back to 1976. While this hearing would be the 30th entry on the log, let this chronology serve as a reminder that this is an old issue and that none of us wish this effort to become just another item on this log of activities.

* And, finally, I offer a very exciting report recently prepared by my Subcommittee. It is a set of model national standards of practice for those who provide guardianship and/or representative payeeship services as a business or not-for-profit enterprise. If these standards were used, we would see fewer exploitative practices concerning the funds of board and care residents under representative payeeships for SSI or other public entitlements. Furthermore, I'm convinced that if they were followed there would be less warehousing of older and disabled Americans in board and care homes.

Thank you.

Board and Care Facilities in New Jersey

A Report

of the

Subcommittee on Housing and Consumer Interests Staff

Select Committee on Aging

U. S. House of Representatives

Congressman James J. Florio

Acting Chairman

Overview Of Staff Findings From Visits To New Jersey Facilities

Subcommittee staff made field visits to six board and care facilities in New Jersey. In addition to the facility visits, the subcommittee has acquired letters of complaints and responses from board and care residents, local social service providers, legal services providers, the Department of Community Affairs, and the Department of Health.

The result is a composite picture of neglect in board and care facilities, incidents of ignoring or blatantly violating residents' rights, poor hygiene, misuse of residents' property and money, poor record keeping, inadequate staff, neglected physical plant, unsatisfactory food services, inadequate nutrition, lack of needed services, boredom, and almost complete disregard for the dignity of elderly and disabled residents.

The following is a summary of findings from the staff visits to the six New Jersey facilities and review of written documents.

Two Residential Health Care Facilities and four Class C boarding homes were visited within the past two weeks. While the staff observed significant differences between each of the facilities visited, they observed and otherwise learned of far more similarities between the facilities regardless of its licensing category. Each facility was not looked at for precisely the same characteristics; staff observed the meal service in some facilities but not in others, the medication distribution system was exmined in several homes but not in all. There was greater availability of residents in some than in others. Residents in some were more eager to talk. And, some facility employees showed a greater willingness to talk or reveal information than staff in other facilities.

Before examining each facility on an individual basis, some common characteristics and general conclusions can be offered.

Overall, the condition and atmosphere of the six facilities can be described as bleak at best. These are each sad places filled with largely sad people. Daily life for many of the residents of these facilities can easily be characterized as simply existing. The residents are of all ages of adulthood and virtually all appeared to be significantly impaired in one way or another; a great majority were likely mentally impaired — certainly a much greater proportion than the 42 percent that was represented in the 1986 New Jersey study of more than 6,000 residents cited in the GAO report. The indications are that a very large proportion of the residents are medicated, often with pyschotropic drugs.

The nearly 300 residents of the facilities are virtually all poor, existing on their SSI payments, of which all but $55 goes each month to pay for their "care."

Inactivity and boredom is pervasive. Virtually no activities outside the "three S's" — sitting, smoking, and seeing TV — were observed or suggested. One facility advertised bingo one day a week. Incredibly, not one piece of reading material was observed in a common area of any of the six facilities — not one newspaper, magazine, or book. There was no music playing. One facility had phonographs, none of which worked. Even TVs, the one form of stimulation outside of conversation, were not readily available. One TV for more than 150 residents in one facility and TVs were for the most part old and wearing out.

This population is essentially alone - they do not, in general, receive visitors. Outside of the subcommittee staff and the local legal advocate, not one visitor was observed in any of the facilities visited.

On-site services were not in evidence although staff were told that some limited services are provided in some facilities, such as a podiatrist in one facility, and a city nurse who visits board and care facilities. It is safe to assume that many of the residents of the visited facilities could benefit from mental health services. Outside of their medications, the availability of mental health-related services seems to be non-existent. One crucial service that was evident, however, was the presence of a legal advocate. Subcommittee staff were accompanied on a visit to each facility by an advocate from the Community Health Law Project. At each site, except one, the advocate knew some of the residents and they knew or recognized her. And in each home, including the one at which the advocate did not know residents, residents actively sought a chat "off in the corner" to seek help with one problem or another. It appeared that it would take more than one advocate to adequately serve the needs of the residents of just these few facilities.

It is clear that far too many residents are fearful about speaking out about their problems. In conversations with subcommittee staff, several specifically said that those who "make waves" find themselves on the street looking for a new place. They realize that finding another facility may be increasingly more difficult (due to urban renewal, the low SSI rates are leading some owners to close down the operation, or even being blacklisted). As David Lazarus of CHLP and others note, these residents are truly dependent upon the operator for virtually everything and "making waves" may be hazardous. Subcommittee staff witnessed a particularly graphic example of the consequence of voicing a concern that is outlined in the profile of facility C below.

Finally, it is the conclusion of subcommittee staff that, at least for the facilities visited (and discussions with various knowledgeable individuals in the state suggests that it is true elsewhere), the notion of residents receiving assistance with personal care is at best a nice concept and in reality is a charade. New Jersey law governing RHCFs requires in regard to "Personal Hygiene" (N.J.A.C. 8:43-5.1):

(a) "Each resident shall receive such daily personal care as needed;

1. Bath: Residents shall be bathed or assisted with baths as necessary.
2. Oral hygiene: Residents shall be assisted with oral hygiene to keep mouth, teeth or dentures clean as necessary.
3. Hair: Residents' hair shall be kept clean and neat.
4. Manicure and pedicure: Fingernails and toenails shall be kept clean and trimmed as necessary.
5. Shave: Men shall be assisted with shaving, or be shaved as necessary to keep them clean and reasonably well-groomed."

With regard to Clothing, section 5.2 states:

"The operator should make certain that residents have appropriate and sufficient clothing for necessary changes and that such clothing is laundered as frequently as necessary."

It is the opinion of subcommittee staff that these provisions are essentially unachievable in the two RHCFs visited.

Background: GAO Report and March 9 Hearing

A General Accounting Office (GAO) report will be released at a Congressional hearing on board and care on March 9, 1989. The report is based, in part, upon findings from a field examination of board and care quality and oversight in six States including New Jersey. The other States were California, Florida, Ohio, Texas, and Virginia. The term "board and care" is generally used to describe "a wide variety of nonmedical community-based residential facilities — group homes, foster homes, adult homes, domiciliary homes, personal care homes, and rest homes." (GAO/HRD-89-50, page 2). The generally accepted distinction between a boarding home and a board and care facility is that the latter provide meals, some form of "protective oversight" over residents by providing supervision of their activities or well-being, and may include assistance with some activities of daily living, ranging from bathing and grooming, to assistance with the taking of medications.

Board and care residents generally have physical limitations and often are mentally disabled. The board and care population consists principally of the elderly, the mentally retarded, and the mentally ill. According to a 1986 needs assessment of board and care residents in New Jersey that is cited by the GAO, about 42 percent of residents "had a psychiatric care history, about 68 percent had a chronic illness, and about 71 percent were on medication."

There is tremendous variation among States as to their regulatory structure governing board and care facilities. Some States do not regulate such facilities, or regulate them in only a minimal way. Of the six States examined by the GAO, two — Ohio and Texas — "have made very limited attempts to identify and license their homes." In comparison, other States appear to have extensive regulatory structures for board and care facilities. The other four States in the GAO study, including New Jersey, indicate that "they have comprehensive licensing criteria and enforcement activity." However, officials from each of the States examined, except New Jersey and California, "expressed concerns about the adequacy of oversight of their board and care industry."

Unlike nursing home residents whose care is financed in very large part by Medicaid, and to a lesser extent Medicare, care for board and care residents is financed almost entirely out of the pockets of the resident. For low-income elders and disabled persons, their income under the Supplemental Security Income (SSI) is used to pay for their board and care stays. States have the option of supplementing this amount with what is known as the State Supplement Program (SSP). Individual residents are entitled to retain a set portion of their payment known as their personal needs allowance (PNA) for their personal use. In New Jersey, the PNA is $55 per month.

New Jersey has two distinct categories of board and care facilities that serve the elderly and other frail or disabled populations. These are:

- o Class C Boarding Home*: For two or more residents who are unrelated to the owner. The minimum required services include meals, shelter, laundry, financial services, such as assistance with dressing, bathing, transportation to health services, and medications.

- o Residential Health Care Facility (RHCFs): For four or more residents unrelated to the owner. The minimum required services are meals, shelter, laundry, one or more personal care services, such as assistance with dressing, bathing, and at least 12 minutes per resident per week of medical supervision and health monitoring by a registered nurse.

Each of the two licensing categories are licensed and regulated by two distinct State agencies. Class C facilities are regulated by the Division of Housing and Development, Department of Community Affairs. RHCFs are regulated by the Health Facilities Evaluation Unit (Bureau of Rooming and Boarding House Standards) of the Department of Health (which also regulates nursing homes). GAO figures show a combined total of 462 board and care facilities in New Jersey with nearly 13,000 beds. Of these, 228 homes are Class C facilities and 234 are RHCFs (more recent date indicates there are now some 240 Class C facilities).

* There are also Class A, B, and D facilities. Class D homes are being phased out and usually are directly affiliated with a State agency that provides services to a distinct population (e.g. mental health). Class A and B homes are less than board and care facilities, providing shelter or shelter and meals only. A noted New Jersey advocate for board and care residents has noted, however, that the Class A facilities may prove to be New Jersey's "Pandora's Box:" There are some 17,000 Class A beds which are settings that provide lodging only, as in various shelters, and other rooming situations. Very little is known about these facilities or those who populate them. How many are elderly or have mental impairments? Are they essentially street people or do they include substantial numbers of working poor? Of these 17,000 beds, how many are occupied by people who truly need to be at a higher level of care?

The SSI/SSP rate differs between the two categories of licensed facility, with the difference reflecting primarily the registered nurse-related services. The Class C SSI/SSP rate is $399.25 per month ($358 SSI and $41.25 SSP) and the RHCF rate is $518 per month. Of these amounts residents retain $55 per month for their personal needs allowance. For those residents who have some form of other income in addition to SSI, the so-called "any income disregard" computation in SSI provides an additional $20 per month to the beneficiary that goes toward the facility payment. The result is that a Class C facility will receive a range of $344-364 per month per beneficiary and a RHCF will receive a range of $463-483 per month.

A major issue facing board and care residents is the level of SSI/SSP payments. This is, of course, of paramount importance to facilities that have a census that consists largely or entirely of SSI beneficiaries. The GAO notes two studies from New Jersey that "found that homes in its board and care programs lost money on residents dependent upon SSI." One industry funded study cited in the GAO report from November 1987 showed that taken together the federal and state SSI rate for RHCF residents "fell $6.68 per day below the average cost of $21.05 per days for 55 such facilities, or a monthly shortfall of about $200." A 1986 Department of Community Affairs funded study "found the 1983 average monthly costs were $39.85 more than the total 1986 SSI benefit available to residents of 20 Class C board and care homes.

It is worth noting that staff determined that in New Jersey on average it costs about $11 per day to board a 70-pound dog. For this, one meal a day, water, and a place to run are provided. In contrast, New Jersey board and care residents dependent upon SSI receive a low of just over $11 to a high of just under $16 for their lodging, meals, and care in a board and care home. And, of course, in states that do not provide a supplement to the Federal SSI level, the daily rates are even lower.

During the site visits two owners discussed their frustration with the current SSI levels and one stated quite categorically that he must sell the facility, if he can find a buyer, because of the economic realities of serving low-income residents. Others in New Jersey have indicated to staff that indications are that facilities are beginning to go out of business or are contemplating it because of these fiscal problems.

The GAO indicates that officials in New Jersey, as well as in California, Florida, and Virginia, "believe they have comprehensive licensing criteria and enforcement activities." In contrast, Texas and Ohio have made "very limited attempts to identify and license their homes" (with an estimated 3,500 unlicensed facilities in the two states). The GAO report indicates that of the six states studied New Jersey is one of only two states in which officials did not express "concerns about the adequacy of oversight of their board and care industry."

New Jersey may be well ahead of many other states in its regulatory structure for board and care homes. A problem frequently cited in many states is that there are many "unlicensed" board and care homes operating. The GAO report and Subcommittee findings suggest that this may well not be a significant problem in New Jersey because its licensing system, particularly since the enactment of the Rooming and Boarding House Act of 1979, has led to the licensing of facilities at the Class A and B levels that are not licensed in most other states.

It is likely, however, that New Jersey shares with other states, at least to some degree, the problem of facilities being licensed at an inappropriate level. It also appears from the GAO report and from discussions with knowledgeable people in New Jersey that state officials have utilized various forms of sanctions to bring poor operators into line and to redress serious problems. New Jersey's system appears to be effective in identifying the most egregious circumstances of poor care and flagrant abuses.

Apparently, many other states cannot make a similar claim. There are very fine board and care homes in New Jersey. While state officials may have justifiable pride in this scenario, the findings of the subcommittee suggest that it would be wrong, irresponsible and, indeed, harmful to suggest or believe that they are no concerns about the adequacy of life, care, or oversight over board and care homes in the state of New Jersey.

As the following narrative indicates, life in some New Jersey board and care homes is anything but something to feel content or satisfied about. In light of conditions that continue to exist in some of the state's facilities, if New Jersey is well ahead of other states, then life for the residents of many board and care facilities in those states must be miserable.

As David Lazarus, Director of Litigation for the Community Health Law Project in East Orange, will testify on March 9, New Jersey has made progress in addressing many of the really egregious conditions and its system may look good in concept and on paper. Nonetheless, he will point out that serious problems remain in ensuring quality care and in protecting the rights of its vulnerable citizens residing in board and care homes.

It is the opinion of subcommittee staff that these provisions are essentially unachievable in the two RHCFs visited.

Facility A

Facility A, a Residential Health Care Facility, was by far the largest facility visited. A former resort hotel, Facility A has a capacity of some 163 residents, with an estimated 150-155 currently residing in the facility. From the observations of staff, this was the worst of the six facilities visited. The facility reeked of cigarette smoke (smoking appears to be the principal activity of the residents) with a thick haze of smoke permeating the common areas. Beyond the fact that some residents were watching television in the large common room (the only TV in the several common areas), the only other activities observed were some residents talking with each other. By and large, most residents simply were sitting. Not one piece of reading material, such as a newspaper or magazine was observed in the facility. One cabinet held several old phonographs, none of which appeared to be functional. A sign in the lobby indicated that bingo occurs on Thursdays.

The age of the residents varied from some young people in their 20's and 30's up to a substantial number of elderly persons. It appears from observation and discussion with staff on duty and a local legal advocate, that most of the residents have mental impairments and many were previously confined in mental institutions. According to facility management, 85-90 percent of residents are dependent upon SSI/SSP.

The physical condition of the facility can only be characterized as old and run down. It is badly in need of paint and patch work, at a minimum. There could be major structural problems as well. It was dirty and soiled but not filthy in most places observed. Cockroaches were seen but, at least during daylight hours, were not evidenced in abundance. One resident's room that staff visited was small, but the resident seemed pleased to have a room to herself. It had, however, a major crack along the ceiling and running down the wall. The room's furnishings were sparse and battered but functional. The sink in the room ran continuously.

The second floor contains the common rooms for the residents (one large room with the TV and two smaller rooms). One of the small rooms, where the soda machine is located, contains the two restrooms for the residents using the floor. Neither had locks on them yet are available to all residents, male and female. While there, staff observed the door to one restroom coming ajar while being used. Neither bathroom was clean but one of the two was especially filthy. There was a hole in the floor which went down to the first floor. Furnishings for the common area's were dirty, torn, and otherwise well worn.

Medications are distributed from behind the desk of the lobby four times daily. Subcommittee staff were present at "meds" time at which the residents lined up at the desk and the line snaked up the stairs as each resident awaited his or her dosage. Their system allows facility staff to note who hasn't taken their dosage and, as staff witnessed, these individuals are then summoned over the loudspeaker to come and get their meds. Medications are kept in a cabinet that has a lock but observation indicates that it was not kept locked (staff asked a question about the meds and a facility staff member simply opened the door to show the contents).

Observed staffing of the facility consisted of two persons, the supervisor and a registered nurse, plus the kitchen help and someone to operate the elevator. New Jersey law requires that an RHCF must provide 12 minutes of nursing-related care per resident per week. For facility A this means some 32 hours of nursing services per week, therefore the R.N. is on duty 8 hours a day, four days a week, to meet this requirement. It is staff's observation that her time is consumed in large part by distributing the medications on the days she is on duty and helping to staff the counter. She did say that a podiatrist visits the facility. It is essential to bear in mind that there are some 150 ambulatory residents in this facility.

Two meals were observed at facility A — lunch on one day and dinner on another. At both meals dessert was served first (a butterscotch-like pudding at lunch and a doughnut or other similar pastry that was clearly not freshly baked at dinner). Many residents proceeded to eat the dessert first. The lunch meal was a large hotdog with sauerkraut and two slices of white bread. The dinner menu was a meager portion of spaghetti or puffed rice cereal (a packet of sugar was on top and when served the milk was poured directly over the sugar packet) or cottage cheese. As the spaghetti was ladled onto the plate, the plates were stacked on top of each other on a cart three deep and then distributed. There seemed to be no attention to temperature control under these circumstances. During the dinner, the cook yelled out that seconds were available in the kitchen and a number of residents immediately rushed to the kitchen. Nonetheless, it appears and some residents said that meals are the major highlight of the day.

Residents were largely disheveled; their clothing was generally quite worn and their hair unkempt and dirty. There was no indication that assistance is provided to residents in their grooming or hygiene as required by New Jersey law (N.J.A.C. 8:43-5.1). One resident was noted as having a large head sore that was oozing and did not appear to have been recently treated.

An announcement over the loudspeaker that the "canteen" would be open for five more minutes drew the attention of Subcommittee staff who then were able to observe some of "canteen time," when the small canteen is open to sell items to residents. Conducted in a room filled with what appeared to be junk, the canteen was operated by the home's supervisor (leaving the R.N. to staff the front counter). The inventory consisted mostly of cigarettes at $1.60 a pack and candy at 60 cents a bar. The operator said that neighboring shops sell to the cigarettes to the residents for $1.70 a pack.

While several residents were willing to talk about their life in the facility and voice significant complaints and concerns, they also said, as the legal advocate reinforced, those who voice complaints are simply told to leave. This is terrifying for many residents who perceive, with merit it seems, that alternative residential environments are not easily available.

Finally, this facility is in a section of the community scheduled for demolition for redevelopment purposes. Options for relocation of the residents are very limited although it is alleged that the owners of this facility have indicated that they may take the residents with them to another facility in Southern New Jersey.

Facility B

Facility B, a Class C Boarding House, has some 37 residents currently residing in it. The on-site supervisor of this facility was the most apprehensive employee encountered at any of the facilities (therefore it was not surprising that the owner of the facility was only person to call the subcommittee subsequent to the visit and express concern about the visit). As a result of the phone call, the facility was notified in advance of a second visit, and both the owner and his son were on premises. The son guided a second tour of the facility.

This facility (its name suggests the image of a seaside resort — it is close to the ocean — that would provide free terry cloth robes) offers instead an example of a facility inept at basic cleanliness and washing and returning residents' laundry. Nonetheless, it was one of the two better facilities visited.

For example, the front room, which is entered upon opening the front door, was relatively tidy and the operators have attempted to provide a bit of color in the furnishings and the chairs were relatively comfortable appearing although certainly showing signs of wear. A menu was posted for the day's meals:

breakfast —	"oatmeal, juice, toast, jelly, tea"
lunch —	"macaroni cheese, spam, corn, bread, oleo, punch, plums"
dinner —	"barley soup, egg salad sandwich, tea, cake"

A meal service was not observed during the visit. The dining room also displayed posted notices about the rights of boarding home residents and New Jersey's abuse reporting law. Unlike the other facilities visited, the floors were segregated by sex. Each floor also had small sitting/TV rooms that were, compared to the other facilities, reasonably tidy. Of particular note was that there were several functioning TVs available in the facility. Finally, the facility was reasonably well-lighted.

As with the other facilities, outside of television, there was no evidence of other forms of activities and no reading material was visible. Very few residents were present in open or common areas, except in the basement which was designated as a separate smoking room. It had a functioning TV and a soda machine. It was, however, nowhere near as tidy as the front room. Several areas of the facility were dirty and in need of repair.

An upstairs large bathroom (contained a couple of showers and toilet) was in particularly bad shape. On the second visit, in response to a subcommittee staff comment, the owner's son said he didn't know why it was open because it was not used by residents — however, staff noticed recently used soap in the shower and a cleanser in a toilet bowl. The bathroom was open on both visits. In another bathroom the only toilet paper present was used toilet paper and there was no soap. Another toilet was completely without toilet paper. Bathrooms were without locks (having floors segregated by sex was certainly a step in the right direction in terms of a hint of privacy and respect for residents, particularly under these circumstances).

The facility has been cited for not adhering to regulations protecting the property of residents based on a complaint forwarded by the Community Health Law Project. The findings of the complaint investigation report of the regulatory agency indicate their view that facility staff were "unclear and unsure of their legal responsibility with residents' laundry." A copy of the Class C regulations was left with "both the owner and the operator so that they may re (sic) reaquainted with our regulations."

Facility C

Facility C, the other RHCF included in the site visits, was the second worst of the six facilities visited. Subcommittee staff note that the facilities they visited that were in the worst condition, from their observations, were the two RHCFs. The staff assumption that the RHCFs — in light of their seemingly higher status in terms of level of care (required to provide 12 minutes of nursing-related services per resident per week) and the significantly higher reimbursement rate (approximately $119 differential) — would appear to be of higher quality, was not borne out by the visits. An official of a national organization representing board and care-type facilities stated to subcommittee staff that New Jersey's RHCF operators certainly think of themselves as a notch above the Class C facility operators.

According to the facility operator the facility had been sanctioned for structural and other problems resulting in the imposition of a limit of 20 residents despite its capacity of 44-50 beds. The upper floor of the facility was posted as off- limits to residents. Staff visited the upper floor finding it to be in a very deteriorated state, including severe water damage to the ceiling, wall and floor. The empty rooms contained bed springs and furnishings in very serious disrepair. In short, it was a mess. In addition, graffiti on a wall prominently displayed obscene ethnic slurs.

Facility C can only be accessed by steps in the front and the back — 7 in front and 5 in back The back stairs seemed to be in disrepair and had no handrail; hopefully it is not used by residents (the back of the facility was very untidy and contained considerable refuse including a refrigerator on its side with the door on and unrestricted access to the back yard). Residents with limited mobility would have difficulty gaining access to the facility.

The only observed common area is the room entered through the facility's front door. Although not terribly dirty, it was spartan and unattractive (e.g. plastic chairs) and contained a television set that a resident said "works sometimes" (it was old with aluminum foil on the rabbit ears), as well as a wall hanging. Ashtrays on the floor were No. 10 size food tins. On the first visit, several residents were just sitting with no activity with the exception of one animated resident who showed us her room and talked about the facility. On the second visit, the TV was on and several residents were watching it.

Two floors contained residents. A resident showed us her room which she said was the largest in the facility. It slept three and was very cramped and untidy but was not as dirty as others seen by the staff. Several bathrooms were quite dirty -- no soap was visible, and they were without locks. Males and females shared the same floors and bathrooms. Staff were unable to locate lights in the halls and stairwells of the second floor and although the visit was made during the daytime it was very dark in these areas. The second floor was considerably dirty with trash strewn in the hallway. Of the facilities visited, this home had the most offensive odors of urine and other matter.

Several rooms on the second floor were unoccupied and in as poor shape as those on the third floor (e.g. bare box springs, battered furnishings). One young male resident was lying on bare box springs in one of the empty rooms with an empty wine bottle on the stand next to him. He said that his room was on the same floor.

The kitchen and dining area, although simple, were relatively clean. The pantry was tidy and consisted primarily of numerous No. 10 tins of beans, pork and beans, and cheese sauce, as well as a tin of garbanzos, apple sauce, two containers of instant mashed potatos, and several unlabeled tins.

While on the second visit to facility C, staff witnessed what they consider to be verbal abuse. A resident came to the desk to ask the supervisor (the only staff person on premises) about her "energy check." The supervisor orally attacked the resident in an exceedingly hostile manner ordering her to get to her room and threatening to throw her out of the facility. The resident, who responded angrily, replied that the operator "can't treat me like a dog. I'm a person too," but then retreated. The operator then commented to subcommittee staff that she was sorry we saw that exchange but that, in effect, "happens around here." (Note the reference to residents' rights below.)

A handwritten note over the supervisor's desk raised significant question about the facility's belief in the privacy rights of residents. New Jersey law governing RHCFs provides that "The operator shall make certain that the life of residents, insofar as privacy is concerned, is respected at all times." (N.J.A.C. 8:43-4.3(b)) Residents Rights provisions require the facility to ensure that each resident "Is treated with consideration, respect, and full recognition of his/her dignity, individuality, and right to privacy..." (N.J.A.C. 8:43-7.2(a)8) The note stated:

> "To all employees when you take a telephone call or when someone comes to see someone write down all messages and be sure that all messages get to (name of supervisor and operator)."

This facility was recently cited for deducting an amount from a resident's personal needs allowance because the resident soiled her mattress due to her incontinence. Further, the facility failed to provide adequate personal care supervision to maintain the resident's good personal hygiene. Facility C has been investigated on other occasions for allegations of improper behavior regarding residents funds. Dipping into a resident's PNA monies significantly reduces their ability to purchase a bar of soap, snacks, cigarettes or other items that they believe enhances their life.

Facilities D and E

Facilities D and E are profiled together because they are under common ownership and are adjacent to each other; facing different streets but with the property backing up to each other.

The sharing of a property line no doubt provides certain advantages to management but clearly results in significant hardship to residents. Facility E lacks a dining area, so residents must walk to Facility D for each of their three daily meals irrespective of the weather outside. It seems likely that residents may miss some meals due to inclement weather such as that experienced over the past couple of weeks along the New Jersey coast.

According to the operator on premises, facility D has 31 residents and facility E has 23 residents. Few residents were observed in facility D while the observed residents of facility E were largely non-elderly. The operator on site at facility D said that his facility "takes people that no one else wants." This operator seemed to have authority over the supervisor at facility E who, when questioned by staff, said that although she had been at the facility for a number of years she was new to the staff role.

Facility E appeared to be in significantly worse condition than facility D but this may be in large part due to the fact that with fewer residents available, there was less interaction with residents and opportunity to view their living environments. Facility E was the worst of the four Class C facilities visited. For example, as previously noted, it lacks the capacity to provide meals to residents. The several bathrooms in the home did not contain a piece of soap nor toilet paper. In addition, locks on bathroom doors were broken and, as in most of the other settings, males and females use the same bathrooms. One toilet had a broken handle with a very sharp jagged edge; a hard push down on it could result in a nasty wound.

The bathrooms in facility D were not much better, lacking soap, toilet paper, and locks. One bathroom door, for example, had a sliding bolt which was missing the piece which the bolt should enter and the door knob was dangling from a large hole in the door. One bathroom without any form of covering on the window is overlooked by an adjacent facility. The window of another bathroom, while covered, was covered by a dirty and torn yellow piece of plastic which may have been a shower curtain.

A resident's room in facility E, occupied by a young mentally ill male, was the worst resident's room visited at any of the six sites. It must be noted, however, that compared to the number of rooms available, few residents' rooms were actually inspected. The sink in this resident's room was filthy and large amounts of porcelin were gone. The single-size mattress was filthy and covered by two dirty and old blankets and a pillow. When asked about the sheets the resident attempted to cover the exposed area of the mattress. When brought to the attention of the supervisor, who entered the room shortly thereafter, she chided the resident claiming he hadn't retrieved his sheets from the laundry (the pillow had a pillowcase on it).

As with each of the other facilities, there was no indication of any available activities beyond watching sitting, television, and smoking.

Subcommittee staff have reviewed complaints formallly filed with an advocacy organization and licensing authorities.
Complaints have been made that staff of facility D have kept up to one-half of a "home energy payment" which, by law, belong to the resident. There have been complaints that facility staff have borrowed large sums of funds (relatively speaking) and have not repaid the borrowed amount. Other instances of finacial coercion of residents have been reported. One resident charged that his car was sold while he was in the hospital. While New Jersey law requires that facilities maintain accurate records of their financial transactions with residents, poor record keeping makes it nearly impossible to fully investigate a complaint of financial mismanagement.

Observations by subcommittee staff coupled with discussion with advocates and a review of some complaints filed concerning facility D suggest that a resident would be lucky to have heat, clean bedding, receive notice of a phone call to him or her made to the pay phone for residents, or even a second cup of coffee with their starch-filled meals.

Facility F

The final site of the visit was to a Class C home. Facility F has 20 residents few of whom were older persons. The owner said he tries to take only those age 40 and over as younger residents are far more difficult to deal with and he worries about them being violent. He said that the residents are mostly on SSI and "100 percent have a psychiatric history."

This facility was the best appearing — and feeling — of the six visited. It was physically a smaller facility than the others, having more of an old home feel. Of particular note, the residents seemed more content than in the other facilities, to the extent that staff could gauge this. Perhaps there was more of a docile feel to facility F. There were no visible attempts by residents to complain about the facility, the care, or the staff, or to ask for help in getting out of the facility. The common area had somewhat of a "family room" feel although it was quite dark. Several residents were in the sitting room watching the television. The owner and his family live on the premises on the top floor. A number of residents gathered about to follow the subcommittee staff member and the accompanying legal services advocate. The owner and the other staff person on premises - the cook, were the friendliest facility personnel encountered. The kitchen and dining room in the basement were tidy and relatively clean.

Nonetheless, facility E was not without problems. It had an old musty smell to it and was shabby in many places. One bathroom, for example, had a dirty, torn bedspread serving as a curtain with a battered venetian blind underneath. The property was surrounded by a high chain link fence topped with three strands of barbed wire that were pointed inward giving them the appearance of being intended to keep people in rather than out.

Medications were contained in an unlocked container with individual drawers labeled for each resident which sat on a table in the dining room. A resident took the subcommittee staff member down to see the medications set-up and to show her own medications. The resident pulled out individuals' drawers including a drawer of one resident who she said no longer is at the facility that contained various prescription containers. One drawer contained, as an example, Lithium, Benzatropine, and Loxitane. Medications for various mental disorders were commonplace.

This facility did post a notice about residents' rights, however, the lower half of the poster containing information as to whom to contact and how (e.g. phone number) had been ripped off.

A considerable amount of time during the visit was spent in discussion with the owner who described his economic difficulties. He was new to the business having acquired the facility four years ago. He said it cost him $200,000 to start the business and that he is barely able to break even and make his mortgage payments. The owner said he is unable to pay staff more than $4 per hour and that he can only get poor help for that wage. He is actively considering giving up on this venture.

TESTIMONY OF

THE HONORABLE MARY ROSE OAKAR

REGARDING THE NEED TO REGULATE BOARD AND CARE HOMES

MR. CHAIRMAN:

THANK YOU FOR THE OPPORTUNITY TO ADDRESS THIS HEARING. AS A SENIOR MEMBER ON THE HOUSE COMMITTEE ON AGING, I WANT TO COMMEND YOU FOR HOLDING THIS JOINT COMMITTEE EVENT. IN MY OPINION, IT WOULD BE VERY USEFUL TO HOLD MORE JOINT HEARINGS IN AN EFFORT TO MORE FORCEFULLY PRESENT THE NEEDS OF THE ELDERLY TO THE AMERICAN PUBLIC. BOTH YOU AND YOUR STAFF HAVE DONE A WONDERFUL JOB PREPARING FOR THIS MEETING.

MR. CHAIRMAN, I BELIEVE THIS HEARING WILL PROVE TO BE A MILESTONE IN AGING COMMITTEE PROCEEDINGS. THE PROBLEM OF QUALITY OF CARE IN BOARD AND CARE HOMES -- SIMILAR TO THE ISSUE OF THE QUALITY OF CARE IN NURSING HOMES SEVERAL YEARS AGO -- MAY PROVE TO BE THE SPARK THAT LEADS TO CORRECTIVE LEGISLATION. I HAVE BEEN OUTRAGED BY THE REPORTS WRITTEN BY THE HOUSE SELECT COMMITTEE ON AGING AND THE GENERAL ACCOUNTING OFFICE. BOTH REPORTS CONTAIN STRONGLY WORDED RECOMMENDATIONS CALLING FOR INCREASED REGULATION AND THE CREATION OF REASONABLE AND ENFORCEABLE STANDARDS FOR BOARD AND CARE HOMES. I STRONGLY URGE THE COMMITTEES TO SERIOUSLY CONSIDER THESE SUGGESTIONS. HOWEVER, I VIEW THIS ISSUE AS A SUBSET OF A LARGER, MORE PERVASIVE PROBLEM.

MR. CHAIRMAN, I BELIEVE THE ISSUE OF BOARD AND CARE QUALITY ASSURANCE IS YET ANOTHER EXAMPLE OF ELDER ABUSE. ELDER ABUSE IS A TERRIBLE SOCIAL PROBLEM THAT HAS YET TO BE EFFECTIVELY

ADDRESSED BY THE CONGRESS. CONSEQUENTLY, I HAVE INTRODUCED A BILL, H.R. 220, THAT WILL BEGIN THE PROCESS OF PREVENTING, IDENTIFYING AND TREATING OF ELDER ABUSE. IT IS A MEASURE I HAVE CONSISTENTLY INTRODUCED TO HELP THE MORE THAN 1 MILLION SENIORS WHO ARE ABUSED EVERY YEAR -- WHETHER THEY ARE PHYSICALLY, PSYCHOLOGICALLY, EMOTIONALLY, OR FINANCIALLY MISTREATED.

SPECIFICALLY, MY BILL CALLS FOR THE CREATION OF A CENTRAL CLEARINGHOUSE WITHIN THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO GATHER AND DISSEMINATE INFORMATION REGARDING THE PREVENTION, IDENTIFICATION AND TREATMENT OF ELDER ABUSE. IN ADDITION, H.R. 220 PROVIDES FOR DEMONSTRATION PROGRAMS AND PROJECTS FOR THE PREVENTION AND TREATMENT OF ELDER ABUSE. FURTHERMORE, THIS BILL PROVIDES INSTRUCTIONS FOR THE DEPARTMENT OF HEALTH AND HUMAN SERVICES TO ASSIST IN THE TRAINING OF PERSONNEL -- WHETHER THEY ARE IN FIELD OF HEALTH, LAW, GERONTOLOGY, SOCIAL WORK OR OTHER RELEVANT PROFESSIONS -- WHO ARE ENGAGED IN ELDER ABUSE PREVENTION.

MR. CHAIRMAN, H.R. 220 IS A REASONABLE AND MUCH NEEDED FORM OF RELIEF FOR OLDER AMERICANS WHO ARE BEING EXPLOITED OR OTHERWISE ABUSED. I URGE THESE IMPORTANT COMMITTEES AND THE CONGRESS TO CONSIDER THIS IMPORTANT MEASURE AS SOON AS POSSIBLE AND I WISH TO SUBMIT THIS TESTIMONY AND A SUMMARY OF H.R. 220 FOR THE RECORD.

THANK YOU.

SUMMARY OF H.R. 220
THE ELDER ABUSE PREVENTION, IDENTIFICATION
AND TREATMENT ACT OF 1989
Introduced by Congresswoman Mary Rose Oakar

NATIONAL CENTER ON ELDER ABUSE

H.R. 220 calls for the creation of a National Center on Elder Abuse. The Center will perform the following functions:

1. Compile, publish and disseminate a summary annually of recently conducted research on elder abuse, neglect, and exploitation;

2. Develop and maintain an information clearinghouse on all programs, including private programs, showing promise of success, for the prevention, identification, and treatment of elder abuse, neglect, and exploitation;

3. Compile, publish and disseminate training materials for personnel who are engaged or intend to engage in the prevention, identification, and treatment of elder abuse, neglect, and exploitation;

4. Provide technical assistance (directly or through grant or contract) to public and nonprofit private agencies and organizations to assist them in planning, improving, developing, and carrying out programs and activities relating to the special problems of elder abuse, neglect, and exploitation;

5. Conduct research into the causes of elder abuse, neglect, and exploitation, and into the prevention, identification, and treatment of elder abuse; and

6. Make a complete study and investigation of the national incidence of elder abuse, neglect, and exploitation, including a determination of the extent to which incidents of elder abuse, neglect, and exploitation are increasing in number or severity.

DEMONSTRATION PROGRAMS AND PROJECTS

The Secretary of Health and Human Services, through the Center is authorized to make grant to, and enter into contracts with, public agencies or nonprofit (or combinations thereof) for demonstration programs and projects designed to prevent, identify, and treat elder abuse, neglect, and exploitation.

Grants may be used for:

1. The development and establishment of training programs for professional and paraprofessional personnel, in the fields of health, law, gerontology, social work, and other relevant fields, who are engaged in or, who intend to work in, the field of prevention, identification, and treatment of elder abuse;

2. The establishment and maintenance of centers, serving defined geographic areas, staffed by multidisciplinary teams of personnel trained in the special problems of elder abuse, neglect, and exploitation cases, to provide a broad range of services related to elder abuse, neglect, and exploitation, including direct support and supervision of sheltered housing programs, as well as providing advice and consultation to individuals, agencies, and organizations which request such services; and

3. Furnishing services of teams of professional and paraprofessional personnel who are trained in the special problems of elder abuse, neglect, and exploitation cases, on a consulting basis, to small communities where such services are not available.

The Secretary of Health and Human Services, through the Center, is authorized to make grants to the States for the purpose of assisting the States in developing, strengthening, and carrying out elder abuse, neglect, and exploitation programs.

Appropriations are authorized.

OPENING STATEMENT
BY THE
HONORABLE HELEN DELICH BENTLEY
FOR THE
JOINT HEARING OF THE SELECT COMMITTEE ON AGING AND THE
SENATE AGING AND HOUSING & CONSUMER INTERESTS SUBCOMMITTEE
ON
BOARD AND CARE FACILITIES

March 8, 1989

I would like to thank the Chairmen for calling this hearing today for several reasons, but there is one which stands out among them all: The several instances of board and care abuse and neglect. Neglect, which I am sure occurs everywhere, is not often brought to light except in the shadow of a tragic fire, like the one occurring recently in the District of Columbia.

Board and care facilities do provide a vital function to society: They allow families, without immediate means to support older family members, alternative housing and care arrangements and they enable feeble elderly to choose residence in places other than State operated nursing homes.

As with any service where those being served are, for the most part, totally dependent on the caregiver, we expect a certain amount of accountability from the provider. The age old debate of whether regulation suffocates and stifles entrepreneurial productivity is relegated to a secondary position as we struggle with the task of making existing facilities safe for older, dependent boarders.

Every so often national news focuses on the most hideous of the board and care inhumanities, thus forcing us to look, if only for a few moments, at the truly powerless in their struggle to find a home in their later years.

I would like to thank the witnesses here today and look forward to hearing their testimony.

# # #

OPENING STATEMENT OF THE HONORABLE RALPH REGULA
RANKING MINORITY MEMBER - 16TH DISTRICT OF OHIO
SUBCOMMITTEE ON HEALTH & LONG-TERM CARE - MARCH 9, 1989

Mr. Chairman:

I commend you for your interest in this matter and the efforts you have taken in conducting this hearing.

The focus of this hearing is to examine the current status of board and care homes in our nation. Today, there are approximately 300,000 unlicensed boarding homes and about 30,000 licensed board and care facilities that include supportive services. An estimated 4 to 4.5 million Americans are already housed in such facilities or at risk for board and care placement.

Federal and State support for board and care home residents has over the past two decades risen to over $7 billion. Over 50% of this is paid by the Federal government through Supplemental Security Income (SSI) payments to individuals. Typically residents of such facilities pay the entirety of their SSI income for rent except for a $60 personal needs allowance. On the average this is $500 a month.

The report which was issued by our Chairman and a parallel study recently completed by the General Accounting Office indicate that there are severe problems in the quality of care offered by many homes. In fact, many accounts of serious abuse are documented. These are the same problems of over a decade ago which remain unanswered.

The number of complaints received by the State licensing offices has increased over 40% since 1982. Yet, the state ombudsmen who are responsible for monitoring the program estimated their staff spend little more than 15% of their work-day concerning the issue.

Clearly, greater direction must be provided by the Federal government under the existing Keys Amendment. Stronger sanctions and specific standards are required. But it is the States who must retain primary oversight over the system. In the State of Ohio, there currently is legislation (HB 253) pending which would address many of these problems by providing for uniform licensure and closer monitoring of potential violations. Both providers and ombudsmen have joined in their support for the concept of uniform licensure. This measure is a positive step in addressing this issue in my state and a model for other jurisdictions.

This is an issue that requires attention in a prompt and expeditious manner. I am confident that the comments and insights of our distinguished panel will assist us in meeting that challenge.

Statement of Robert A. Borski
Hearing of the
Subcommittee on Health and Long-term Care
of the
House Select Committee on Aging
March 9, 1989

Mr. Chairman, I want to thank you for calling this joint hearing to investigate the quality of care of older Americans in "board and care" homes across the United States. I commend you for your outstanding dedication to protecting the frail elderly and uncovering these critical concerns.

As you know, and as the General Accounting Office report indicates, there is little oversight of so-called "board and care" homes across America. These homes provide various degrees of non-medical services to older Americans including room and board, some protective services, and assistance with eating, bathing and moving around. Many of the residents of these homes are poor and frail yet regulation and licensing of the homes is haphazard at best.

An appalling horror story about one home in California made national headlines last fall. As the story unfolded in the press, more and more bodies were found in the yard of the house. It was revealed that the owner was killing senior citizens to steal their meager Social Security and Supplemental Security income checks. By the end of the investigation, seven bodies were discovered. While horror of that magnitude may not exist elsewhere, the GAO and the Subcommittee on Health have uncovered many cases of abuse and neglect. This hearing will help bring to light the areas with the most severe problems so that we can take appropriate actions to protect older Americans.

These investigations have uncovered unsanitary living conditions, inadequate nutrition, lack of heat in the winter, suffocating temperatures in the summer, abuse and neglect in all forms. Each of these abuses is only one part of a myriad of concerns surrounding "board and care" facilities. Such conditions are totally unacceptable.

I am pleased to join you here today to listen to the testimony of these witnesses and have them relay their experiences to us. It is clear that we must take action to ensure that poor and frail elderly are protected from persons who would prey on their vulnerability.

I commend you again Mr. Chairman, for the leadership you have shown by investigating "board and care" facilities and all the work you have done to uncover these abuses and I look forward to our hearing today.

The CHAIRMAN. We will now hear from Senator Bill Bradley of New Jersey. Following Senator Bradley's statement, we will receive the testimony of our first witness, Congressman Pepper.

Senator Bradley.

STATEMENT OF SENATOR BILL BRADLEY

Senator BRADLEY. Thank you very much, Mr. Chairman. I want to commend you and Congressman Florio for opening this joint hearing. The issue really does need to have attention devoted to it.

Board and care homes provide residences and support for poor, elderly, chronically ill and mentally ill patients. Nationally, there are about one million beds available in about 100,000 facilities. Less than half of these facilities are licensed and the conditions in some facilities sound horrible, as we have heard already today and as we will hear I am sure, from many of the witnesses.

Investigations which were conducted by the GAO, by Congressman Florio, Congressman Pepper and by others clearly indicate that the standards are not strong enough or stringent enough for these facilities. Owners and operators of facilities that milk the properties and jeopardize the lives of their sick and elderly residents should be prosecuted to the fullest extent of the law. These people should not be preying off the elderly, they should be in jail.

We would be remiss if during our deliberation we did not take into account the full dimensions of the problems in board and care homes. If we want to upgrade standards, expand oversight and improve the overall quality of board and care homes, the cost of these homes for the poor, elderly and disabled residents will more than likely increase. Unless we can find ways to increase the incomes of residents, we could very well price some of them out of their residences. We cannot truly say we have dealt with the problem of board and care homes until we have addressed the question of elderly income.

So, Mr. Chairman, let me thank you again for holding this hearing. I think that these efforts will shed light on an enormously important and hidden national issue.

The CHAIRMAN. Thank you Senator Bradley.

Gentlemen, of the committees, before we hear from Congressman Pepper, it gives me great pleasure to make a special presentation to this very distinguished man. For the history buffs in the audience today, let me reemphasize one very salient fact. Congressman Pepper is of course associated with the State of Florida which he has represented with such distinction for so many years. Let me note, if I might have this personal privilege, his career did not begin in Florida. It started in Arkansas.

When he moved to the State of Arkansas to launch his political career, then Professor Pepper taught at the University of Arkansas Law School for a one-year period. One of his very distinguished students at that time, was a former United States Senator from our State: the Honorable J.W. Fulbright.

Today it gives me great pleasure to present to Congressman Pepper and to make him the Honorary Chairman of the Senate Special Committee on Aging. Congressman Pepper, Democrats and Republicans alike would like to honor you and your years of distin-

guished service, not only to the elderly, but to all Americans. At this time if you might, sir, come forward and receive a presentation from our committee.

I would like to read this very brief inscription: In appreciation for his unmatched dedication to serving older Americans, the Senate Special Committee on Aging hereby proclaims Congressman Claude Pepper as the Honorary Chairman of this committee. Congressman Claude Pepper—let's give him a round of applause. [Applause.]

Needless to say, Congressman Claude Pepper is as much an institution in this city as the Washington Monument, and we look forward to hearing his statement.

Senator HEINZ. Mr. Chairman, if I might add——

The CHAIRMAN. Yes, Senator Heinz.

Senator HEINZ. It is also good to get some young blood on this committee.

The CHAIRMAN. It surely is.

Senator SHELBY. Mr. Chairman, if I can——

The CHAIRMAN. Yes, Senator Shelby.

Senator SHELBY. If I can add one little tidbit—you mentioned Arkansas. Congressman Pepper is originally from Alabama; he is from Tallapoose County. He is a graduate of the University of Alabama, undergraduate, and the Harvard Law School. Then he found his way to Arkansas.

The CHAIRMAN. Congressman Pepper, we look forward to your statement.

STATEMENT OF HON. CLAUDE PEPPER, A U.S. REPRESENTATIVE FROM THE STATE OF FLORIDA AND CHAIRMAN, SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE

Mr. PEPPER. Mr. Chairman, and members of the joint committee, I am proud, as a member of this Select Committee on Aging and Chairman of the Subcommittee on Health and Long-Term Care of the House, to be able to join you this morning in having this very meaningful hearing. I am profoundly grateful to the distinguished Chairman, Senator Pryor of Arkansas, for his gracious remarks and for his generous bestowal upon me of the honorary title of Chairman of the Special Committee on Aging of the United States Senate. I am very proud to be in such good company. My mother told me when I was a little boy, she said, "Son, always try to run with the best people." Today I am in the best company I could be in, and I am very grateful for the opportunity.

May I say that ten years ago the distinguished Chairman, the Senator from Arkansas, and I worked together in the House with respect to matters of the aging. He was the first member of the House to advocate the creation of the Select Committee on Aging. He did not quite succeed but he was the one who was the motivating force for the effort that did later succeed. I later became chairman of that committee for about seven years. So I am very proud to be in such good company with this distinguished Chairman. I hope all of us together can progress the cause of the needy, the tragically needy elderly of our country.

Mr. Chairman, I am today releasing the report of my subcommittee's investigation of board and care facilities in our country. Our report, entitled "Board and Care Homes in America: a National Tragedy," will give new meaning to the phrase, "Bring me your tired, your poor." I would like to insert the executive summary of our report in the hearing record at this point and file officially the report of our Subcommittee that made this investigation.[1]

[The report follows:]

[1] The report "Board and Care Homes in America: A National Tragedy," U.S. House of Representatives, Subcommittee on Health and Long-Term Care. Report #101,711 is available from the House Select Committee on Aging.

BOARD AND CARE HOMES IN AMERICA: A NATIONAL TRAGEDY

EXECUTIVE SUMMARY

"Board and care" is the broad term used to describe facilities that provide shelter, food and protection to frail and disabled individuals. For a variety of reasons, board and care has become a burgeoning industry in America serving as the repositories of the mentally ill and others we have chosen to ignore. An estimated 1 million Americans currently reside in 68,000 licensed and unlicensed board and care facilities, and 3.2 million more of our citizens are currently at risk for board and care placement.

Board and care is not just a housing and a long-term care issue. It is an economic issue as well. Federal and State support for board and care home residents has, within the last two decades, climbed to over $7 billion dollars.

What is the Nation receiving for its money?

This report explores that, and related questions.

It concludes that public policy has failed to produce safe and affordable environments for chronically ill or disabled and poor Americans.

It concludes that it is difficult for most Americans to comprehend how a vast segment of its people can be disenfranchised, warehoused and exploited by the unscrupulous. But such warehousing, exploitation and abuse in the board and care industry is far from an isolated and localized problem involving a few mentally impaired elderly. Rather, fraud and abuse in board and care homes is a nationwide scandal of epic proportions.

In order to determine the nation's effectiveness in coming to grips with this national tragedy, the Subcommittee undertook the following steps:

—Collected, reviewed and tabulated all letters and case histories received by the Subcommittee over the last 10 years, in addition to reviewing all hearings and reports on abuse in board and care homes by Congressional committees and administrative agencies;

—Prepared and sent a questionnaire to all State Licensing Offices and State Ombudsmen at the Chairman's request. The responses to these questions were tabulated and appear later in this paper. The questionnaire can be found in Appendix III and IV;

—Conducted follow-up telephone interviews with State Licensing Offices three times over a 10-year period;

—Reviewed all books, periodicals and newspaper references to board and care homes in the possession of the Library of Congress;

—Reviewed and summarized case histories of abuse forwarded to the Subcommittee by the States. These case histories can be found later in this report;

—Communicated with numerous organizations and service providers representing the elderly and the disabled, to ascertain their views on the problem of abuse in board and care homes;

—Conducted 46 unannounced inspections of board and care homes, both licensed and unlicensed, in nine States and the District of Columbia between December 1988 and February 1989; and

—Interviewed literally thousands of board and care residents in nine different States and the District of Columbia to determine their socioeconomic background.

The Subcommittee concluded that the Nation's over 1 million elderly, disabled, and mentally ill currently residing in board and care homes in America—and the more than 3.2 million more at risk of placement in such homes—are frequently the victims of fraud, neglect and abuse. Warehoused and drugged, this vulnerable population is usually unaware that their rights to board, care and protection can easily be circumscribed by unscrupulous home owners or greedy and uncaring home managers., Unfortunately, the Federal Government, who pays the lion's share of the Nation's $7 billion board and care bill through the Supplemental Security Income program, does not have any standards in place to protect this needy population. The Federal remedy for abuse which does exist, the Keys Amendment enacted in 1978, has proven ineffective and unenforceable. Unless corrective action is taken, millions of elderly and needy will continue to suffer the indignities of a society which prefers to shun them rather than ensure them the security they so rightly deserve.

Chapter I of this report discusses the growth of board and care in America. It concludes that the increase in board and care homes in America is due to a variety of factors. First, the deinstitutionalization of the mentally ill in the 1960s resulted in the movement of the mentally ill, previously assumed to need institutionalization, into the community. Since 1969, the States have reduced their mental patients from about ½ million to just over 100,000 in 1987. Meanwhile the cost to maintain an individual in a mental institute increased substantially—from $5,626 in 1969 to $41,131 in 1987. So, there was a great incentive for the States to move mental patients out of their State supported mental hospitals and back into the community to be supported by the Federal Government through the Supplemental Security Income (SSI) program. Second, about the same time the States started shifting mental patients back into the community, Medicare and Medicaid nursing home regulations evolved resulting in many nursing homes no longer able to meet standards of participation. Instead of nursing home patients, board and care homes began opening their doors to patients who did not need to be living in "skilled care" environments. Third, the enactment of the SSI program in 1972 created the financial incentive for home operators to open their doors to the mentally ill and disadvantaged. Lastly, the increase in the AIDS epidemic, the shortage of nursing home beds, the rapidly growing elderly population, and

the general shortage of long-term care services, will serve to stimulate an increased need for board and care homes in future years.

Chapter II provides a definition of board and care homes and the residents of such homes. It describes how over a million elderly and disabled Americans are living in such homes today at a cost of roughly $7 billion a year. It explains how another 3.2 million Americans may also be the residents of such facilities or are at risk of such placement. The Federal Government is the primary payer of such care—paying the lion's share of over 50 Percent. The Subcommittee found that the number of licensed board and care homes has jumped over 71 percent since 1984—from 23,274 to 39,986. The number of unlicensed homes was set by the States to be about 28,000.

Roughly two-thirds of all residents are elderly and female—this is partly due to their life-expectancy. Women live longer, on the average, than men. The residents are generally in a position of dependency, that is they are relying on others for their care and their protection.

Typically board and care residents pay the entirety of their supplemental security income for rent in a board and care home, excluding the Federal personal needs allowance which averages about $60 a month. The average monthly rent is about $500 a month.

Chapter III makes for unpleasant reading. It presents summaries of major newspaper exposes on board and care abuses. It also presents summaries of examples of abuse from every part of the United States provided to the Subcommittee primarily by Ombudsmen and State Licensing Offices. Hundreds of accounts of abuse ranging from sexual abuse to theft of personal needs allowance are provided. The most prevalent abuses, according to State authorities, were drug mismanagement and malnutrition.

Chapter IV details the Subcommittees investigation of board and care facilities. staff of the Subcommittee, accompanied by State Ombudsmen or other appropriate State authority, visited 46 licensed and unlicensed board and care home on an unannounced basis in nine States (Alabama, California, Florida, Illinois, Maryland, Louisiana, New York, New Mexico, Virginia, Washington, D.C.). The data received from these visits supports the following conclusions:

—More than half of the board and care residents came from a mental institution. Most residents were female and elderly.

—Over 72 percent rely on SSI for the entirety of their income. They pay about $578 (less the personal needs allowance of $35) for rent. Most residents make the home's manager their representative payee. Less than 25 Percent once worked, less than 5 Percent are currently employed. Residents come primarily from mental institutions. Other referrals come from hospitals, detoxification centers, nursing homes and the street.

—Residents have few rights. In those States which do require the Ombudsman to respond to complaints, the effectiveness of this remedy depends on State regulation. For example, in States which license homes with four or more residents, a resident in a home with only three has no recourse within the State.

—Inadequate staffing was a major problem followed by overdrugging. Where homes were understaffed—the primary means of containing or controlling residents was chemical (drugs) or physical restraints.

—Most homes were not equipped with fire safety equipment, were unsanitary and ill-kept, and were roach and pest infested.

—The Subcommittee observed at least one incident of fraud, waste or abuse in literally every State that was visited. In **New York**, we found Medicaid cards being sold to providers. In **New Mexico**, 10 Alzheimer's patients were found bound to their wheelchairs in spite of a law requiring residents to be able to leave the home under emergency situations on their own accord. In **California**, we investigated the murder of seven residents by an ex-felon manager who then cashed their Social Security checks. In **Maryland**, an owner continued to house 11 residents in her burnt out home—one resident was robbed of his possessions. In **D.C.**, a bed-bound elderly woman was found by Subcommittee staff lying in her own urine begging for food in her roach-infested three-story walk-up room. In **Illinois**, we found 200 residents of a home required to turn over their small personal income allowance to the home operator. In **Florida**, we investigated the deaths of two residents, one of whom died of a drug overdose, and the other who died bedbound, tied, with multiple decubitus ulcers. In **Louisiana**, city officials closed down a pest-infested, unlicensed board and care home following the Subcommittee's unannounced inspection unveiling deplorable and life-threatening conditions. One resident died and others were hospitalized within hours of the Subcommittee visit. In **Alabama**, a home cited for numerous violations by the Subcommittee burned down injuring two of the homes frail elderly residents several days after the visit. In **Virginia**, we found 11 former mental patients, two of whom required skilled nursing care, warehoused in an old row house.

Chapter five analyzes data received from State Licensing Offices and State Ombudsmen regarding their experiences with board and care homes in their respective States. We found:

—The number of licensed board and care homes in the United States has nearly doubled from 23,474 to 39,986 in the period from 1984 to 1988. The population in these licensed homes has increased over the same period from 376,436 to 573,943. In addition there are many individuals living in unlicensed homes. The data shows that there are some 4 million people at risk for board and care home placement.

—The population of board and care homes is for the most part economically disadvantaged. The States estimate that 57 Percent of board and care homes receive Supplemental Security Income (SSI) benefits.

—The number of complaints received by the State licensing offices has increased from 6,963 in 1982 to 11,011 in 1987. Sixty percent of the State Ombudsmen also said that they were experiencing increasing difficulties with board and care homes.

—A high percentage of both State licensing offices and State ombudsmen reported problems with such abuses as: Physical and

Sexual Abuse of Residents, Neglect, Malnutrition, Resident Death Due to Improper or Inadequate Care, Overcrowding, Inappropriate Placement, Improper Administration of Drugs, Misappropriation of Funds. In addition, the number of States reporting these abuses has not decreased between 1984 and 1988.

—Despite the many problems States identified with board and care homes in their States, it is still not a priority for most ombudsmen. The ombudsmen estimated that on average their staffs spent just 16 Percent of their time on board and care issues. One third of the ombudsmen said that they spent less than 5 Percent on board and care.

—The States are cognizant of their own deficiencies in dealing with the serious problems in the board and care industry. Two-third of the sate ombudsmen said their State's system for regulating board and care homes was inadequate.

Chapter VI discusses Federal action with respect to board and care in America and how the Keys Amendment enacted in 1976 has been unenforceable and totally ineffective. It has had no impact on improving the conditions in the board and care industry. Chapter VII summarizes a report to the Chairman of the Subcommittee on Health and Long-Term Care by the General Accounting Office on Board and Care in the United States.

Chapter VIII provides a summary of the Subcommittee's inquiry and its conclusions. Chapter IX sets forth a number of policy options for consideration of the Congress, Federal Agencies, the States, the board and care industry, and the general public. **The primary action that should be taken by the Federal Government to help ameliorate the problems discussed in this report should be the establishment of minimum national standards of care to be met by all facilities housing and providing some assistance to 2 or more elderly or disabled individuals unrelated to the owner or operator. In establishing the standards, the Congress may wish to consider calling upon the Institute of Medicine of the National Academy of Sciences to convene an expert panel (as they did so successfully with nursing home reform) to develop such standards.**

Other recommendations by the Subcommittee to the Congress should include: lifting the Supplemental Security Income level for eligible residents of licensed board and care facilities; enacting legislation to cover care in the home for chronically ill Americans to avoid premature placement in a board and care home; improving the ability of the State Ombudsman to provide advocacy for this vulnerable population; and require that Medicare participating hospitals discharge patients only to licensed board and care homes.

The report calls upon the Inspector General of the Department of Health and Human Services to aggressively monitor, investigate and prosecute cases of fraud and abuse and neglect in board and care homes. It calls upon the Social Security Administration to reform and monitor their representative payee system; and it calls upon the Administration to restore adequate staffing to the department responsible for monitoring the representative payee system.

Lastly, among its many recommendations, the report calls upon the Department of Housing and Urban Development to increase its housing options for the elderly and disabled and it asks the States to promptly implement and aggressively enforce national minimum standards for board and care homes and employ a sufficient number of inspectors to accomplish this task.

Chapter X is a display of photographs which were taken by Subcommittee staff during its inspection of board and care homes throughout the United States detailing conditions.

Mr. PEPPER. Whenever it pleases the distinguished former chairman of the special committee, Senator Heinz, we will jointly release the report of the GAO which he and I jointly requested on this very vital matter.

We began our investigation ten years ago. We contacted the regulatory authorities in all 50 States in 1979, 1984, and 1988. We also surveyed the ombudsmen, those entrusted with responding to complaints of abuse in board and care homes. To validate our findings we conducted unannounced visits in 1988 and 1989 to both licensed and unlicensed board and care homes. In all, we interviewed over 2,500 residents in 46 homes in ten States—Alabama, Florida, California, Illinois, New York, Maryland, Virginia, Louisiana, New Mexico and the District of Columbia.

We found that most of the one million elderly, disabled and mentally ill persons who reside in board and care homes are being warehoused in understaffed, unregulated, shoddy and unsafe facilities. Although the abuse is so broad and systemic as to be evident in every State of the Union, neither the State Governments nor the Federal Government, which combined spend an estimated $7 billion annually on these facilities, have evidenced any concern for their residents' safety and welfare, leaving this vulnerable population largely unprotected and exploited.

We found that board and care is a growing industry, fueled in part by the need for States to save money. Over the last two decades, the States have been under tremendous pressure to shift thousands of mental patients, the elderly and handicapped out of State mental hospitals, which are expensive for the States to operate, and into board and care homes, which cost the States little. Our report details the latest figures which show the States have reduced their mental patients from 500,000 in 1969 to only 100,000 in 1987. At what cost are the States obtaining the savings in money that they are achieving by turning these miserable people out into the disgraceful care of these homes? Meanwhile, the cost to maintain an individual in a mental institution has increased substantially, from $5,000 in 1969 to $41,000 in 1987.

As you can see, therefore, there is tremendous incentive for the States to move people out of mental institutions and place them in board and care homes where the cost of their care can be shifted to the Federal supplementary security income or SSI program.

Also adding to board and care growth was the evolution of medicare and medicaid nursing home regulations, resulting in many nursing homes no longer being able to meet standards of participation. Thus, many substandard nursing homes have converted into board and care homes.

Another factor fueling the growth in board and care includes the enactment of the SSI program in 1972, creating the financial incentive for home operators to open their doors to the mentally ill and disadvantaged. Lastly, the uncontrolled spread of the AIDS epidemic, the shortage of nursing home beds, the rapidly growing elderly population, and the general shortage of long-term care services, will serve to stimulate and increase the need for board and care homes in future years.

We found that what the States call board and care homes varies widely from State to State. For example, they are called rest homes

in Massachusetts, shelter care facilities in Illinois, domiciliaries in New York, and board and care homes in the District of Columbia. I would like to submit with my testimony a complete listing of what States call board and care homes at this point in the hearing record.

The CHAIRMAN. Without objection.

[The testimony of Mr. Pepper and the list of board and care homes follow:]

FOR IMMEDIATE RELEASE
MARCH 9, 1989

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OPENING STATEMENT OF
THE HONORABLE CLAUDE PEPPER, CHAIRMAN,
HOUSE SELECT COMMITTEE ON AGING SUBCOMMITTEE ON
HEALTH AND LONG-TERM CARE
BEFORE THE
JOINT HEARING
OF THE
HOUSE AGING SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE
AND HOUSING AND CONSUMER AFFAIRS
AND THE
SENATE SPECIAL COMMITTEE ON AGING
ON

"BOARD AND CARE HOMES IN AMERICA: FAILURE IN PUBLIC POLICY"

MR. CHAIRMEN. LADIES AND GENTLEMEN. I AM RELEASING TODAY THE REPORT OF MY SUBCOMMITTEE'S INVESTIGATION OF BOARD AND CARE FACILITIES IN OUR COUNTRY. OUR REPORT, ENTITLED "BOARD AND CARE HOMES IN AMERICA: A NATIONAL TRAGEDY," WILL GIVE NEW MEANING TO THE PHRASE "BRING ME YOUR TIRED, YOUR POOR." I WOULD LIKE TO INSERT THE EXECUTIVE SUMMARY OF OUR REPORT IN THE HEARING RECORD AT THIS POINT.

WE BEGAN OUR INVESTIGATION TEN YEARS AGO. WE CONTACTED THE REGULATORY AUTHORITIES IN ALL 50 STATES IN 1979, 1984, AND 1988. WE ALSO SURVEYED THE OMBUDSMEN -- THOSE ENTRUSTED WITH RESPONDING TO COMPLAINTS OF ABUSE IN BOARD AND CARE HOMES. TO VALIDATE OUR FINDINGS WE CONDUCTED UNANNOUNCED VISITS IN 1988 AND 1989 TO BOTH LICENSED AND UNLICENSED BOARD AND CARE HOMES. IN ALL, WE INTERVIEWED OVER 2,500 RESIDENTS IN 46 HOMES IN TEN STATES INCLUDING ALABAMA, FLORIDA, CALIFORNIA, ILLINOIS, NEW YORK, MARYLAND, VIRGINIA, LOUISIANA, NEW MEXICO AND THE DISTRICT OF COLUMBIA.

WE FOUND THAT MOST OF THE ONE MILLION ELDERLY, DISABLED AND MENTALLY ILL PERSONS WHO RESIDE IN BOARD AND CARE HOMES ARE BEING WAREHOUSED IN UNDERSTAFFED, UNREGULATED, SHODDY AND UNSAFE FACILITIES. ALTHOUGH THE ABUSE IS SO BROAD AND SYSTEMIC AS TO BE EVIDENT IN EVERY STATE OF THE UNION, NEITHER THE STATE GOVERNMENTS NOR THE FEDERAL GOVERNMENT, WHICH SPEND AN ESTIMATED $7 BILLION ANNUALLY ON THESE FACILITIES, HAVE EVIDENCED ANY CONCERN FOR THEIR RESIDENTS' SAFETY AND WELFARE, LEAVING THIS VULNERABLE POPULATION LARGELY UNPROTECTED AND EXPLOITED.

WE FOUND THAT BOARD AND CARE IS A GROWING INDUSTRY, FUELED IN PART BY THE NEED FOR STATES TO SAVE MONEY. OVER THE LAST TWO DECADES, THE STATES HAVE BEEN UNDER TREMENDOUS PERSSURE TO SHIFT THOUSANDS OF MENTAL PATIENTS, THE ELDERLY AND HANDICAPPED OUT OF STATE MENTAL HOSPITALS AND INTO BOARD AND CARE HOMES. OUR REPORT DETAILS THE LATEST FIGURES WHICH SHOW THE STATES HAVE REDUCED THEIR MENTAL PATIENTS FROM 500,000 IN 1969 TO ONLY 100,000 IN 1987. MEANWHILE, THE COST TO MAINTAIN AN INDIVIDUAL IN A MENTAL INSTITUTION INCREASED SUBSTANTIALLY -- FROM $5,626 IN 1969 TO $41,131 IN 1987.

AS YOU CAN SEE, THERE IS TREMENDOUS INCENTIVE FOR THE STATES TO MOVE PEOPLE OUT AND PLACE THEM IN BOARD AND CARE HOMES WHERE THE COST OF THEIR CARE CAN BE SHIFTED TO THE FEDERAL SUPPLEMENTARY INCOME (SSI) PROGRAM. ALSO ADDING TO BOARD AND CARE GROWTH WAS THE EVOLUTION OF MEDICARE AND MEDICAID NURSING HOME REGULATIONS RESULTING IN MANY NURSING HOMES NO LONGER ABLE TO MEET STANDARDS OF PARTICIPATION. THUS, MANY SUBSTANDARD NURSING HOMES HAVE CONVERTED INTO BOARD AND CARE HOMES. ANOTHER FACTOR FUELING THE GROWTH IN BOARD AND CARE INCLUDE THE ENACTMENT OF THE SSI PROGRAM IN 1972 CREATING THE FINANCIAL INCENTIVE FOR HOME OPERATORS TO OPEN THEIR DOORS TO THE MENTALLY ILL AND DISADVANTAGED. LASTLY, THE INCREASE IN THE AIDS EPIDEMIC, THE SHORTAGE OF NURSING HOME BEDS, THE RAPIDLY GROWING ELDERLY POPULATION, AND THE GENERAL SHORTAGE OF LONG-TERM CARE SERVICES, WILL SERVE TO STIMULATE AN INCREASED NEED FOR BOARD AND CARE HOMES IN FUTURE YEARS.

WE FOUND THAT WHAT STATES CALL "BOARD AND CARE" HOMES VARIES WIDELY FROM STATE TO STATE. FOR EXAMPLE, THEY ARE CALLED "REST HOMES" IN MASSACHUSETTS, "SHELTER CARE FACILITIES" IN ILLINOIS, "ADULT CONGREGATE LIVING FACILITIES" IN FLORIDA, "DOMICILLIARIES" IN NEW YORK, AND "BOARD AND CARE HOMES" IN THE DISTRICT OF COLUMBIA. I WOULD LIKE TO SUBMIT WITH MY TESTIMONY A COMPLETE LISTING OF WHAT STATES CALL "BOARD AND CARE" HOMES AT THIS POINT IN THE HEARING RECORD.

WE FOUND THAT BOARD AND CARE RESIDENTS, LARGELY ELDERLY, FEMALE AND DEPENDENT, TYPICALLY TURN OVER THE ENTIRETY OF THEIR SSI CHECK -- WHICH AVERAGES ABOUT $500 EXCLUDING THEIR PERSONAL NEEDS ALLOWANCE OF $35 -- TO HOME OWNERS. MORE THAN HALF OF THE RESIDENTS CAME FROM A MENTAL INSTITUTION. THE REST, FROM HOSPITALS, NURSING HOMES AND THE STREETS. WE FOUND THAT MOST HOMES WERE NOT EQUIPPED WITH FIRE SAFETY EQUIPMENT, WERE UNSANITARY AND ILL-KEPT, ROACH AND PEST-INFESTED.

WE OBSERVED AT LEAST ONE INCIDENT OF FRAUD, WASTE AND ABUSE IN LITERALLY EVERY STATE THAT WE VISITED. IN NEW YORK, WE FOUND MEDICAID CARDS ILLEGALLY SOLD TO PROVIDERS WHO THEN BILLED MEDICARE FOR SERVICES NEVER RENDERED. WE ALSO FOUND ABOUT 600 RESIDENTS IN THREE FACILITIES WAREHOUSED AND IN THE WORDS OF ONE HOME OWNER, "DRUGGED THREE TIMES A DAY WHETHER THEY NEED IT OR NOT." IN NEW MEXICO, 10 ALZHEIMER'S PATIENTS WERE FOUND BOUND TO THEIR WHEELCHAIRS IN SPITE OF A LAW REQUIRING RESIDENTS TO BE ABLE TO LEAVE THE HOME UNDER EMERGENCY SITUATIONS ON THEIR OWN ACCORD. WE ALSO FOUND DRUGS IMPROPERLY STORED CREATING LIFE-THREATENING SITUATIONS. IN CALIFORNIA, WE INVESTIGATED THE MURDER OF SEVEN RESIDENTS BY AN EX-FELON MANAGER WHO CONTINUED TO CASH THEIR SOCIAL SECURITY CHECKS LONG AFTER THEY DIED. WE WILL HEAR TODAY FROM THE ONE RESIDENT WHO LIVED BECAUSE HE DIDN'T TURN OVER HIS CHECK TO HER. WE ALSO FOUND A 95-YEAR OLD WOMAN WHO HAD BEEN BEATEN AND DRAGGED ACROSS THE FLOOR BY HER MANAGER. IN MARYLAND, AN OWNER CONTINUED TO HOUSE 11 RESIDENTS IN HER BURNT OUT HOME THAT LACKED FIRE SAFETY EQUIPMENT -- ONE RESIDENT WAS ROBBED OF HIS POSSESSIONS. IN THE DISTRICT OF COLUMBIA, A BED-BOUND ELDERLY WOMAN WAS FOUND BY SUBCOMMITTEE STAFF LYING IN HER OWN URINE BEGGING FOR FOOD IN HER ROACH-INFESTED, THREE-STORY, WALK-UP ROOM. IN ILLINOIS, WE FOUND 200 RESIDENTS OF A HOME REQUIRED TO TURN OVER THEIR SMALL PERSONAL INCOME ALLOWANCE TO THE HOME OPERATOR. WE ALSO WERE TOLD OF HOME OWNERS RECRUITING AND SIGNING UP THE HOMELESS IN ORDER TO CASH THEIR CHECKS WHICH WOULD BE SENT TO THEIR BOARD AND CARE HOME. YET NO EFFORT WAS MADE TO ASSURE THE SHELTER THEY PURCHASED. IN FLORIDA, WE INVESTIGATED THE DEATHS OF TWO RESIDENTS, ONE OF WHOM DIED OF A DRUG OVERDOSE, AND THE OTHER WHO DIED BEDBOUND, TIED, WITH MULTIPLE DECUBITUS ULCERS. IN ANOTHER HOME, WE FOUND OUT HOW PROFITABLE SUCH HOMES CAN BE. WHILE THE OWNER SKIMPED ON THE QUALTIY OF CARE PROVIDED FOR HIS ELDERLY RESIDENTS, HE LIVED LAVISHLY OFF THEIR SSI -- PURCHASING A LIMOUSINE, POWER BOAT AND VAN WHICH HE PARKED CONSPICUOUSLY OUTSIDE HIS ROACH-INFESTED BOARD AND CARE HOME. IN LOUISIANA, CITY OFFICIALS CLOSED DOWN A PEST-INFESTED, UNLICENSED BOARD AND CARE HOME FOLLOWING THE SUBCOMMITTEE'S UNANNOUNCED INSPECTION UNVEILING DEPLORABLE AND LIFE-THREATENING CONDITIONS. ONE ELDERLY WOMAN WE FOUND LYING IN HER OWN URINE, DIED, AND OTHERS WERE HOSPITALIZED WITHIN HOURS OF THE SUBCOMMITTEE VISIT. IN ALABAMA, A HOME CITED FOR NUMEROUS VIOLATIONS BY THE SUBCOMMITTEE, INCLUDING FLOORS COVERED WITH HUMAN WASTE AND INOPERATIVE UNSANITARY TOILETS, BURNED DOWN INJURING TWO OF THE HOMES FRAIL ELDERLY RESIDENTS SEVERAL DAYS AFTER THE VISIT. IN VIRGINIA, WE FOUND 11 FORMER MENTAL PATIENTS, TWO OF WHOM REQUIRED SKILLED NURSING CARE, WAREHOUSED IN AN OLD ROW HOUSE. NUMEROUS OTHER VIOLATIONS WERE RECORDED BY THE SUBCOMMITTEE IN PHOTOGRAPHS WHICH FILL OVER 200 PAGES OF OUR REPORT.

UNFORTUNATELY, THE STATES CONFIRM THAT THE INCIDENCE OF ABUSE, RANGING FROM NEGLECT TO DEATH, ARE INCREASING AND ARE NOT LIKELY TO ABATE.

IN 1986, I JOINED MY COLLEAGUE HERE IN THE SENATE, THE RANKING MINORITY MEMBER OF THE SPECIAL COMMITTEE ON AGING JOHN HEINZ, IN CALLING UPON THE GENERAL ACCOUNTING OFFICE TO LOOK AT THE CHARACTERISTICS AND NEEDS OF RESIDENTS IN BOARD AND CARE FACILITIES, TO GATHER INFORMATION ON THE SIZE OF THE INDUSTRY, AND TO INVESTIGATE THE ROLE OF THE STATES AND THE FEDERAL GOVERNMENT IN MONITORING THE CARE THAT THESE INDIVIDUALS RECEIVE. THE GAO REPORT, WHICH WE ARE RELEASING TODAY, FOUND THAT THE KEYS ADMENDMENT ENACTED IN 1972 TO PROTECT RESIDENTS OF BOARD AND CARE HOMES HAS PROVED TO BE INEFFECTIVE AND IN MANY STATES IT IS SIMPLY UNENFORCED. IN ADDITION, STATES CONTINUE TO FIND SERIOUS PROBLEMS IN SOME LICENSED BOARD AND CARE HOMES, INCLUDING PHYSICAL ABUSE, UNSANITARY CONDITIONS, AND THE LACK OF MEDICAL ATTENTION. SADLY, THE GAO REPORT VALIDATES OUR SUBCOMMITTEE'S FINDINGS.

WHAT SHOULD BE DONE? THE FEDERAL GOVERNMENT SHOULD ADOPT STANDARDS TO PROVIDE FOR THE ADEQUATE PROTECTION AND CARE OF BOARD AND CARE RESIDENTS IN THE SAME MANNER THAT WE REQUIRE STANDARDS OF CARE BE MET IN OUR NATION'S NURSING HOMES. OVERALL, STATE OVERSIGHT OF BOARD AND CARE HOMES IS ATROCIOUS. TEN STATES HAVE NO STANDARDS AT ALL. WE MUST ESTABLISH AND ENFORCE NATIONAL MINIMUM STANDARDS OF CARE AND PROTECTION (INCLUDING A BILL OF RIGHTS FOR RESIDENTS) FOR ALL HOMES PROVIDING CARE TO TWO OR MORE UNRELATED ELDERLY OR DISABLED INDIVIDUALS RECEIVING SSI. ONCE PROPERLY LICENSED, THEN WE SHOULD ALLOW RESIDENTS TO RETAIN THEIR ELIGIBILITY FOR RECEIPT OF BENEFITS THEY WOULD HAVE RECEIVED IN THEIR HOMES SUCH AS FOOD STAMPS, PUBLIC ASSISTANCE, AND ENERGY ASSISTANCE. WE SHOULD INCREASE THE MINIMUM SSI PAYMENT FOR RESIDENTS OF LICENSED BOARD AND CARE HOMES. SEVENTY PERCENT OF ALL RESIDENTS PAY RENT WITH THE ENTIRETY OF THEIR SSI CHECKS, THE NATIONAL MINIMUM FOR WHICH IS $360 A MONTH. LASTLY, STATES NEED TO MAKE A DETERMINED EFFORT TO TRACK AND CLOSE DOWN, IF NECESSARY, UNLICENSED AND ILLEGAL BOARD AND CARE HOMES.

I LOOK FORWARD TO HEARING THE TESTIMONY OF TODAY'S WITNESSES AND TO THE ENACTMENT OF NEEDED REFORM IN THIS AREA.

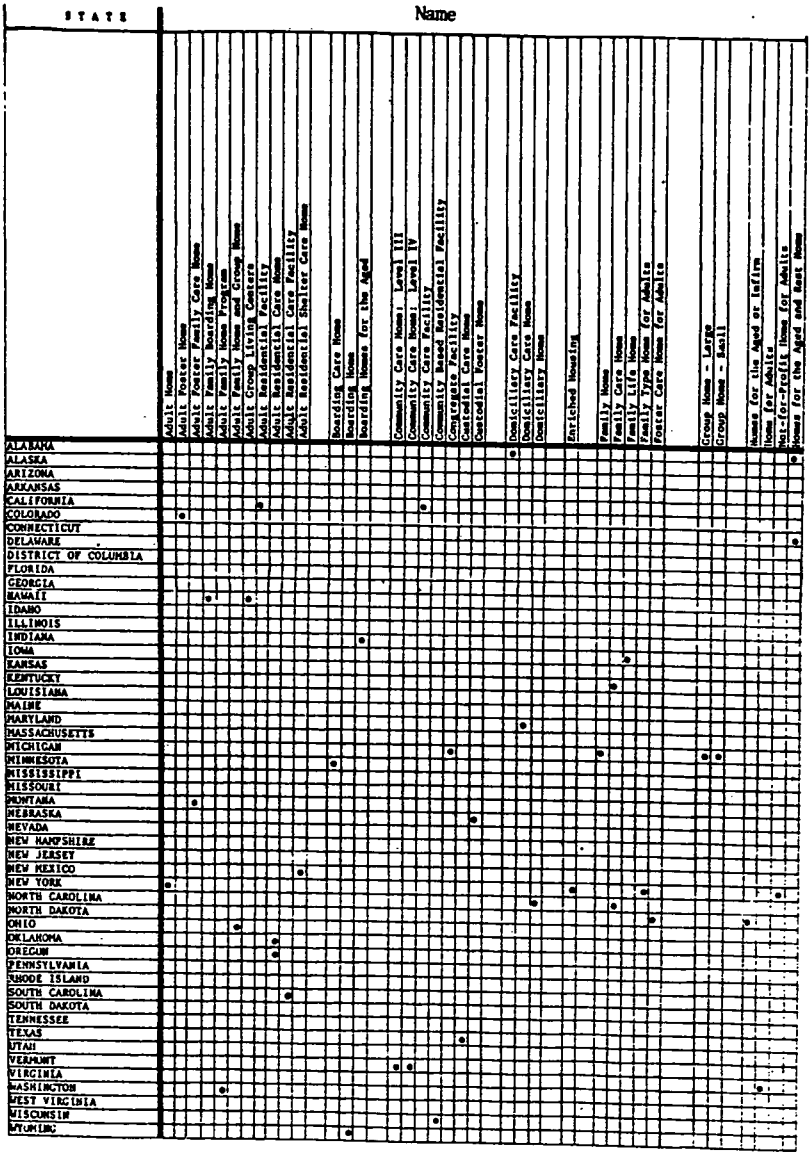
Number of Inpatients in State Mental Hospitals: 1969, 1978, 1987

State	1969	1978	1987
Alabama	7,601	2,255	2,077
Alaska	674	87	170
Arizona	1,141	519	337
Arkansas	1,460	221	284
California	18,118	5,237	5,896
Colorado	10,317	1,148	846
Connecticut	6,068	2,350	2,340
Delaware	1,140	530	518
Florida	9,562	5,337	3,748
Georgia	7,635	5,139	4,256
Hawaii	581	150	238
Idaho	527	179	170
Illinois	28,233	10,540	4,014
Indiana	16,730	5,271	2,342
Iowa	2,230	1,207	852
Kansas	5,592	1,385	1,285
Kentucky	3,479	898	803
Louisiana	4,676	2,074	1,756
Maine	2,726	747	589
Maryland	7,161	3,518	2,770
Massachussetts	21,000	3,292	2,482
Michigan	12,293	4,880	4,104
Minnesota	3,792	1,550	1,526
Mississippi	5,955	2,207	1,738
Missouri	7,496	2,570	2,186
Montana	1,376	855	345
Nebraska	1,685	560	603
Nevada	439	106	82
New Hampshire	2,074	588	518
New Jersey	22,657	6,253	4,616
New Mexico	700	254	219
New York	70,765	27,116	23,693
North Carolina	22,507	2,950	2,992
North Dakota	1,208	627	526
Ohio	16,934	5,275	4,304
Oklahoma	3,854	1,999	1,221
Oregon	3,360	1,175	834
Pennsylvania	27,536	10,280	8,803
Rhode Island	1,881	944	422
South Carolina	5,805	3,673	2,929
South Dakota	1,229	489	378
Tennessee	6,713	2,839	1,822
Texas	14,253	5,620	5,411
Utah	1,284	350	293
Vermont	1,079	315	192
Virginia	11,338	4,963	3,652
Washington	4,252	1,156	1,258
West Virginia	3,950	1,497	1,022
Wisconsin	10,908	682	945
Wyoming	435	210	277
District of Columbia	5,111	2,165	—
Total	427,709	146,232	114,685
Average	8,386	2,867	2,294

Average Cost to Keep an Individual in a Mental Hospital, 1969–87

STATE	Cost per year per inpatient		
	1969	1977	1987
Alabama	$2,124	$15,903	$36,230
Alaska	14,385	60,225	74,497
Arizona	5,009	21,366	48,538
Arkansas	8,432	28,134	—
California	8,694	22,780	35,569
Colorado	19,829	43,824	59,229
Connecticut	7,603	23,798	39,413
Delaware	7,300	20,761	53,137
Florida	3,293	14,146	37,887
Georgia	2,200	3,498	28,791
Hawaii	6,500	29,565	36,036
Idaho	7,300	18,250	50,691
Illinois	6,304	43,828	36,157
Indiana	4,376	15,593	28,948
Iowa	8,600	21,200	31,504
Kansas	7,949	20,838	34,485
Kentucky	2,607	3,687	53,053
Louisiana	5,840	20,714	41,792
Maine	2,974	20,049	43,139
Maryland	4,214	16,519	45,187
Massachussetts	4,425	21,485	34,898
Michigan	6,169	26,324	58,670
Minnesota	5,500	16,790	36,653
Mississippi	2,022	9,023	10,033
Missouri	5,898	19,225	30,945
Montana	3,900	21,000	46,402
Nebraska	5,475	14,674	39,270
Nevada	6,830	36,835	—
New Hampshire	3,600	19,700	46,045
New Jersey	5,421	18,202	35,233
New Mexico	4,573	15,896	—
New York	7,665	21,973	45,574
North Carolina	3,362	18,890	56,933
North Dakota	5,676	14,848	53,392
Ohio	3,467	17,265	45,311
Oklahoma	4,015	16,425	57,702
Oregon	6,390	17,130	39,738
Pennsylvania	4,570	22,867	49,385
Rhode Island	5,074	18,146	50,812
South Carolina	2,504	11,349	26,346
South Dakota	3,697	12,629	26,141
Tennessee	5,186	29,872	38,508
Texas	2,679	16,775	32,511
Utah	2,900	9,004	42,760
Vermont	4,132	23,240	50,188
Virginia	2,654	11,508	32,631
Washington	7,880	20,052	36,496
West Virginia	3,180	17,079	24,678
Wisconsin	9,700	30,400	33,346
Wyoming	5,811	20,889	38,252
District of Columbia	7,019	33,069	—
Total	286,927	1,067,146	1,933,136
Average	5,626	20,924	41,131

WHAT STATES MAY CALL "BOARD AND CARE FACILITIES"



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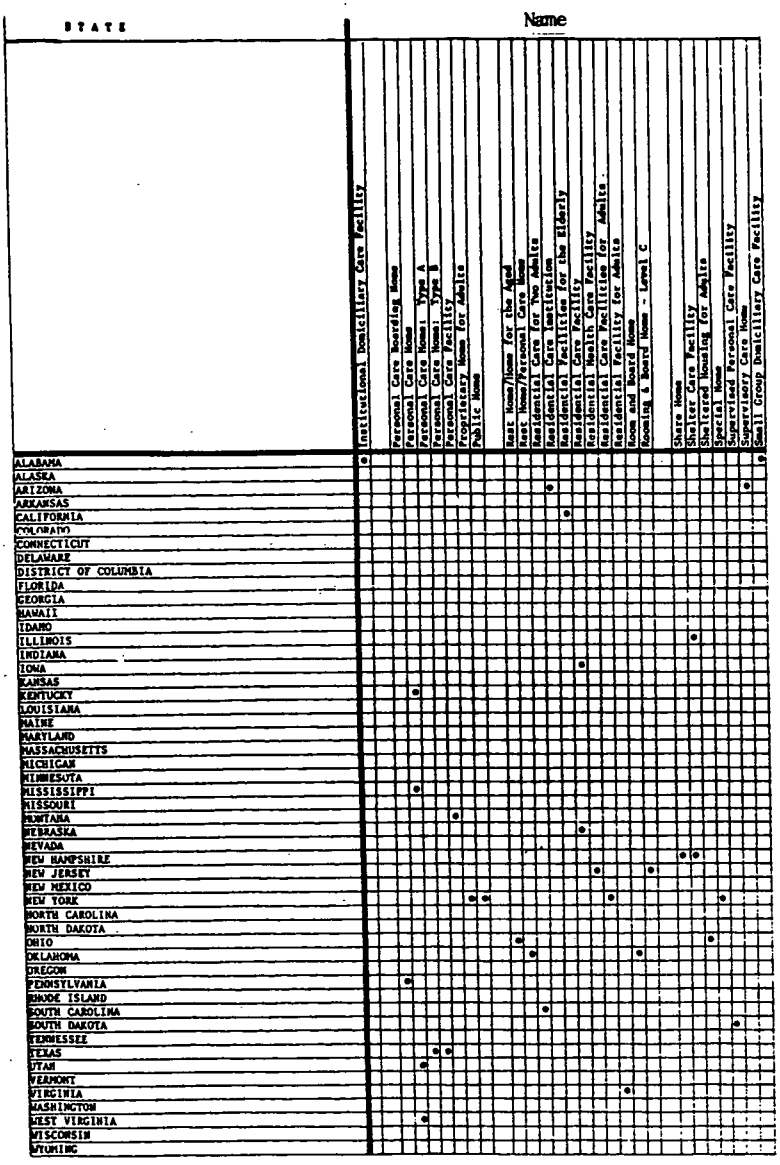

WHAT STATES MAY CALL "BOARD AND CARE FACILITIES"

STATE	Adult Foster Homes	Adult Residential Care Center/Home Serving Mentally or Emotionally Disturbed	Boarding Home for the Mentally Retarded	Family Home	Foster Family Home	Family Care Home/Foster Home	Group Home for the Mentally Ill	Group Home for the Mentally Retarded	Group Home for the Developmentally Disabled	Group Home	Minimally Supervised Group Home	Halfway Homes for the Mentally Ill, Mentally Retarded, and Physically Handicapped	Residential Facility	Residential Treatment Centers for Emotionally Disturbed Children and Adolescents	Residential Care Facility for the Mentally Retarded	Residential Care Facility for the Developmentally Disabled	Residential Care Facility for the Mentally Retarded and Developmentally Disabled	Rehabilitation Facility	Semi-Independent or Supportive Group Living Program	Supervised Living Facility	Specialized Children's Home	Supportive Living Facility for the Mentally Ill	Small Family Home	Therapeutic Room and Board Homes	Transitional Living Group Home	Training Home
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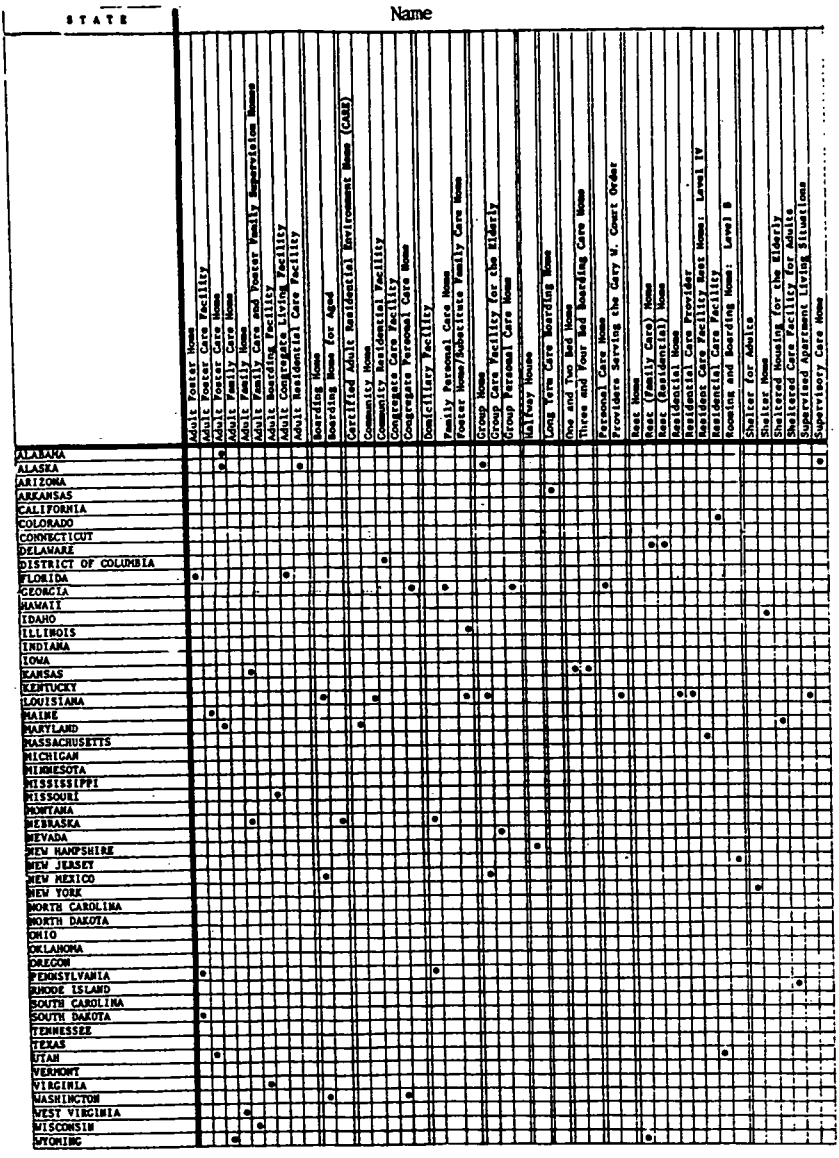
WHAT STATES MAY CALL "BOARD AND CARE FACILITIES"



WHAT STATES MAY CALL "BOARD AND CARE FACILITIES"

STATE	Name																															
	Alternative Care Facility	Alcoholism Quarterway House	Alcoholism Halfway House	Alcohol and Drug Abuse Treatment Facility	Alternative Living Facility for the Developmentally Disabled	Adult Foster Care Facility	Adult Foster Homes for Persons with Severe Mental Disorders	Adult Foster Home - Relative		Behavior Development Program		Community Based Facility for the Mentally Disabled	Community Group Home for Persons Who are Developmentally Disabled	Community Home	Community Living Facility	Community Living Program	Congregate Living Facility	Community Living Arrangements	Community Living Arrangements for the Mentally Ill	Community Living Facility for the Mentally Ill	Community Mental Health Residential Treatment System	Community Residential Facility (Group Home for the Developmentally Disabled)	Community Residential Programs for the Mentally Retarded	Community Residences (Supervised and Supportive Residences)	Community Residences for the Developmentally Disabled or Mentally Retarded	Community Residences	Community Residential Rehabilitative Services for the Mentally Ill	Community Training Homes for Mentally Retarded and Autistic People	Community Residential Mental Retardation Facility		Developmental Training Home	Drug Treatment Center
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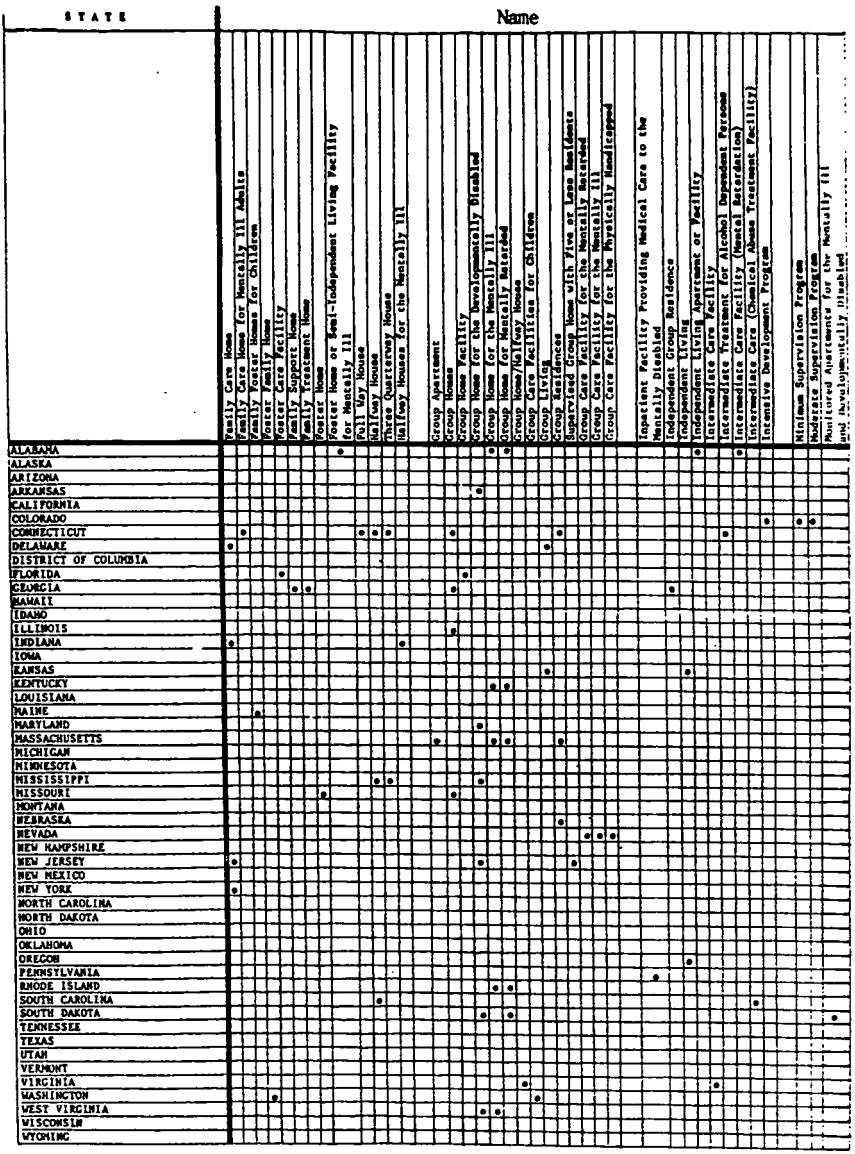

WHAT STATES MAY CALL "BOARD AND CARE FACILITIES"

STATE	Name																																		
	Private Care Facility (Mental Health Care)	Public and Private Residential Care Facilities Serving the Mentally Retarded	Psychiatric Group Home		Residential Facilities for the Mentally Ill	Residential Care Facility for the Mentally Retarded and Developmentally Disabled	Residential Facility for the Developmentally Disabled	Residential Group Care Facility for Children	Residential Treatment Facility	Residential Drug Abuse Program	Specialized Residential Care Facility for the Mentally Retarded	Residential Schools	Residential Facilities and Services for the Physically Handicapped	Residential Rehabilitation Center	Residential Care Center	Residential Treatment and Rehabilitation Facility	Respite Care	Residential Facilities for Inebriate and Drug Dependent Persons		Social Emotional Development Program	Semi-Independent Living	Skill Development Home	Special Living Arrangement Services	Substance Abuse Treatment and Rehabilitation Facility	Sub-Acute Detoxification Facility	Supervised Apartments or Sheltered Apartments	Supervised Apartments for the Mentally Ill and Developmentally Disabled	Supervised Group Home with Five or Less Residents		Transitional Domiciliary Facility	Transitional Residential Facility for the Mentally Ill	Transitional Living Home for the Mentally Ill	Transitional Home for the Mentally Ill	Transitional Living Facility for the Mentally Ill	Treatment Centers for Persons with Alcohol Problems or the Chemically Dependent
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Mr. PEPPER. Thank you, Mr. Chairman.

We found that board and care residents, largely elderly, female and dependent, typically turn over the entirety of their SSI check, which averages about $500 excluding their personal needs of $35, to the home. Now we know, Mr. Chairman, that the minimum SSI benefit is about $360 a month, but the State supplements that somewhat. So generally the amount that the patients turn over to their board and care homes is around $500, less $35. More than half of the residents of these homes come from mental institutions. The rest come from hospitals, nursing homes and the streets. We found that most homes were not equipped with fire safety equipment, were unsanitary and ill-kept and were roach and pest-infested.

We observed at least one incident of fraud, waste and abuse in literally every State that we visited.

In New York, we found medicaid cards illegally sold to providers who then billed medicaid for services never rendered. We also found about 600 residents in three facilities warehoused and in the words of one home owner, "drugged three times a day whether they need it or not." Incidentally, Mr. Chairman and members, we did not find any staff to speak of any one of these ten State board and care homes that we visited. They relied primarily on drugging these people to keep them quiet in the absence of staff people to look after them.

In New Mexico, ten Alzheimer's patients were found bound to their wheelchairs in spite of a law requiring residents to be able to leave the home on their own accord in emergency situations. We also found drugs improperly stored creating life-threatening situations.

In California, and we are going to hear from one of the people who survived it, we investigated the murder of seven residents by an ex-felon manager who continued to cash their Social Security checks long after they died. By the way, Mr. Chairman, one of the things that we recommend is that the Social Security Administration follow up more carefully when authority is given to anybody to cash a Social Security check. We have to make sure that proper use is made of that Social Security money—whether it is appropriately expended or not. We will hear today from the one resident who lived because he did not turn over his checks to that woman in Sacramento who allegedly killed her boarders. In another State, we found a 95-year-old woman who had been beaten and dragged across the floor by her manager and we have a picture of that pitiful lady.

In Maryland, an owner continued to house 11 residents in her burned out home that lacked fire safety equipment. One resident was robbed of all his possessions.

In the District of Columbia, a bed-bound elderly woman was found by subcommittee staff lying in her own urine begging for food in her roach-infested, three-story, walk-up room. That was in our city of Washington, D.C., the capital of the United States of America.

In Illinois, we found 200 residents of a home forced to turn over their small personal income allowance to the home operator. We also were told of home owners recruiting and signing up the home-

less in order to cash their checks which would be sent to their board and care home. Yet no effort was made to assure the shelter they purchased.

In Florida, we investigated the deaths of two residents. One died of a drug overdose, and the other died bed-bound, tied down, with multiple decubitus ulcers. In another home, we found out how profitable board and care can be. While the owner skimped on the quality of care provided for his patients, outside the home—and we have the picture—were parked a Cadillac, a speed boat, a van and two motorcycles. In other words, the proprietor was doing very well, but the patients on the inside were doing very poorly.

In Louisiana, city officials closed down a pest-infested, unlicensed board and care home following the subcommittee's unannounced inspection unveiling deplorable and life-threatening conditions. One elderly woman we found lying in her own urine died, and others were hospitalized within hours of the subcommittee visit. I could not help but think as I looked at the picture of this lady lying there pitifully in her bed with urine all over it that at one time this was a beautiful lady. You can tell that she was at one time a lovely person. Imagine that she had to come to that kind of miserable end to her life.

In Alabama, a home cited for numerous violations by the subcommittee, including floors covered with human waste and inoperative unsanitary toilets, burned down injuring two of the homes' frail elderly residents. This occurred several days after the subcommittee's visit.

In Virginia, we found 11 former mental patients, two of whom required skilled nursing care, warehoused in an old row house. Numerous other violations were recorded by the subcommittee in photographs which fill over 200 pages of our report.

Unfortunately, the States confirm that the incidence of abuse, ranging from neglect to death, are increasing and are not likely to abate.

In 1986, I joined my colleague here in the Senate, the ranking minority member of the Special Committee on Aging, John Heinz, in calling upon the General Accounting Office to look at the characteristics and needs of residents in board and care facilities. They were asked to gather information on the size of the industry and to investigate the role of the States and the Federal Government in monitoring the care that these individuals receive. The GAO report [2] which we are releasing at the pleasure of the distinguished Senator from Pennsylvania, found that the Keys Amendment, enacted in 1972 to protect residents of board and care homes, has proved to be totally ineffective and in many States it is simply unenforced. In addition, States continue to find serious problems in some licensed board and homes, including physical abuse, unsanitary conditions, and the lack of medical attention. Sadly, the GAO report validates our subcommittee's findings.

Now in conclusion, Mr. Chairman, what should we do? The Federal Government should adopt standards to provide for the adequate protection and care of board and care residents in the same

[2] The GAO report "Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met" No. GAO/HRD 89-50 is held in committee files.

manner that we require standards of care to be met in our nation's nursing homes.

You may recall that not too long ago, we found in the nursing homes of this country conditions in many instances as bad as the conditions we found in these board and care homes. We then provided money to the States to carry on proper inspection of these homes and then we provided for supplemental Federal inspections following up the State inspections. Those State inspections were often made after notice was given to the institution that an inspection would be made—not a very good system. We now have a better nursing home situation in America because of what the Federal Government has done.

We also require, as you will recall, the posting in every nursing home of a bill of rights, to let the patients who are in these nursing homes know what their rights are. We propose that a similar program be initiated with respect to these board and care homes.

We propose that we call upon the States to conduct more vigorous inspections and not to allow any board and care home to exist without being licensed by the State.

We further propose that we provide some additional money to the States to help them carry out effective inspections, but we also provide supplementary inspections ourselves through Federal agencies as we currently inspect our nursing homes around the country.

Then we propose also, Mr. Chairman and members of the committee, that once we require these institutions to be licensed and once they are under proper inspection, we should provide a little better income for the residents, as has been suggested here this morning. We should allow them to continue to receive food stamps, medical benefits and other benefits that they would receive if they were not in a board and care home.

One night I gave a talk before one of the associations of board and care homes. They very strongly argued that if we would allow these people to continue to receive the benefits that they received before they went into the board and care home that would give them a supplemental income to pay for the homes which could in turn provide better care for them.

So, what we propose to do, Mr. Chairman, is primarily to apply to board and care homes the requirements that we now have for the nursing homes of the country, give them a bill of rights, give them an increased income and add an injunction to the States not to brutalize these poor people by turning them out to these board and care homes from costlier institutions to save money for the States. At what a terrible price they achieve those financial savings.

The last thing, Mr. Chairman, is we need to provide for the needy people of this country adequate low-cost housing, which as you know we have not provided. I hope that we are beginning to provide a better housing program for the poor and the homeless, which will include facilities for people of this character who need the help that we propose.

Mr. Chairman, I don't want to take too much of your time but I have these pictures and I will just briefly refer to them.

There is a picture of the lady I spoke about—she's lying in her urine. She died some time after our representative was there and made these pictures.

Above is a woman bound. Do you see that cord around her waist? She's bound into her wheelchair. That was in a State which by law forbids that kind of thing. These people are denied the right to get out of the wheelchair when they want to.

This is the ceiling of a residents room in a Maryland board and care home after a fire there. The home is still not equipped with fire safety equipment and escapes and is unlicensed, yet it housed 11 elderly people. That was the kind of place in which they were housed.

This is a bed in one Alabama board and care home. The bed was urine-stained, feces-stained and covered with blood. The bed was covered with and surrounded by piles of putrid-smelling, unwashed clothes. The home was reported to local authorities but burned down before appropriate action could be taken.

The subcommittee found drugs in a New Mexico board and care home stored improperly. Some of these drugs required refrigeration. The cook told the subcommittee staff that he supervised the administration of medication to the residents in spite of the fact that it is illegal to do so under New Mexico State statutes. Residents of such homes must be able to administer their own drugs.

In Miami, Florida, we found this oxygen machine in the room of a board and care resident. Residents who require such skilled care should be in a nursing home not in a board and care home where they don't have staff to take care of such people.

This Alabama home's toilet was found covered with urine and feces. The floors of the home were found littered with human waste. The smell was masked only by the constant smoking of residents. Those are some of the inside conditions of one of the home's rooms.

This 84-year-old woman was found emaciated in a Birmingham, Alabama, board and care home. She hadn't eaten in days, suffered from severe hypertension, and had not received appropriate medical care. She was hospitalized following our visit.

Do you see those three people? Obviously, they have all been drugged. This is the place where they said, "We give them drugs three times a day whether they need them or not. They keep them quiet by giving them drugs." We complained about the conditions there and the operator said, "You can't put us out of business, who would take these people? It costs the State four times as much to care for them. We just drug them and keep our fingers crossed."

Here, at the top of this picture, is the man that I told you about in Miami who ran one of these board and care homes. Do you see, on the left is a speed boat, in the middle is a Cadillac, next to the Cadillac are two motorcycles, and next to them is a van. The proprietor seemed to be doing all right, but the miserable patients on the inside were not doing all right.

The bottom picture is a home in Sacramento, California, where a former felon, a woman, was the manager and proprietor. She is reputed to have killed seven of the occupants of that home and cashed their Social Security checks for some time after they were murdered. We have a witness here today who lived in that home.

He survived because he wouldn't give her his Social Security checks. That's the place where that occurred.

The subcommittee talked to this 95-year-old woman on the left. Just before our representative was there, she had been beaten and dragged across the floor by the manager of this board and care home. You can see what a miserable situation it is. The other picture on the right is the back of the woman showing the bruises that she had sustained by the treatment that they inflicted upon her.

Here, in the top picture, is the Washington home where on the third floor an elderly woman was found bound and crying out for food and drugged by the management of that institution. She was found in an insect-infested and putrid room. That's the top picture.

Here's another one—at the bottom is a home in Chicago. The subcommittee found this home to have only two phones for over 200 residents, no working elevators, a library with no books, exposed wiring, and an unsanitary environment.

That's a little summary, Mr. Chairman, of the miserable conditions that we found for these people.

The CHAIRMAN. Congressman Pepper. We are grateful to you not only for your presentation but for your long contribution to the issues of growing old in America. We have a chair for you at the dais and would be honored if you would join us.

Mr. PEPPER. Thank you very much.

The CHAIRMAN. Thank you, Congressman Pepper.

I would like to call the second panel.

Alice Lippold is a former resident of a board and care home in Washington. She is accompanied by Anne Hart, the D.C. ombudsman. She will be followed by John Sharp, a resident of a board and care facility in Sacramento, California. Mrs. Ima Ring, of Indianapolis, Indiana, follows Mr. Sharp. She is here to talk about the circumstances surrounding her brother's death in a Michigan board and care home. Ms. Julie Oetting, an ombudsman from Birmingham, Alabama, follows Mrs. Ring. In addition to her testimony, Ms. Oetting has an audio tape that she will play for the committee during the course of her testimony. Finally, we will hear from Mr. David Lazarus. Mr. Lazarus is the director of litigation at the Community Health Law Project in East Orange, New Jersey. He will discuss his work on behalf of the board and care residents.

We will ask Mr. Lazarus to make the first statement.

STATEMENT OF DAVID LAZARUS, DIRECTOR OF LITIGATION, COMMUNITY HEALTH LAW PROJECT, EAST ORANGE, NJ

Mr. LAZARUS. My name is David Lazarus and I have been the Director of Litigation for the Community Health Law Project for the last 12 years. The Law Project is New Jersey's largest non-government public interest law firm employing about 30 attorneys and 30 advocates in our four offices around the State. We were initially sponsored in 1977 by the State of New Jersey, the American Bar Association and the New Jersey State Bar Association to provide legal and advocacy services to the mentally ill and elderly.

Today, we represent about 3,500 other elderly and disabled persons per year most of whom are poor. Many of our clients live in

board and care facilities and over the years we have had a great deal of contact both positive and negative with the owners and operators, State officials, and other community service providers. I have written portions of New Jersey's laws regulating the board and care industry and for the last 10 years have been one of the few non-governmental members of the State's interdepartmental committee responsible for suggesting regulations and coordinating governmental and industry efforts.

Our attorneys and advocates have represented many clients in board and care facilities in disputes with the operators. Cases have included theft of Social Security's or other clients' funds, unconscionable rent increases, illegal evictions, work for pay lower than minimum wages and incidents of abuse and exploitation. In one case we represented an 86-year-old woman who paid her entire life savings of $32,000 and her monthly Social Security check to the operator of a board and care facility in exchange for a life tenancy. Two years later she was evicted. We found in the course of representing her that the operator had several felony convictions and although State authorities were informed, he still operates that facility today. Our staff has witnessed assaults on residents and reported them to the proper authorities. But after investigation, these incidents were dismissed as unsubstantiated without the investigator even interviewing our staff.

I could go on describing a litany of horror stories and incidents of abuse and exploitation in board and care facilities but I am sure you will hear that from others. I would prefer to focus on New Jersey's laws, who the residents are that live in these facilities, why it is impossible to provide appropriate standards of care and rehabilitation and why board and care facilities have become bargain basement warehouses for the mentally ill and disabled elderly. I would also like to provide you with some recommendations, but please remember that even if you forget all else: We spend less for the board and care of a disabled adult or senior citizen than for the board and care of a dog in a kennel.

New Jersey's laws governing board and care facilities on paper are probably the strongest in the nation. They provide for licensing of all facilities and their operators, standards of care appropriate to residents' needs, inspection by State officials, mandated reporting of incidents of abuse and exploitation and investigation, the power to fine and place facilities in receivership and mandated social and health services. But unfortunately for many residents what exists on paper in New Jersey's laws and what exists in reality are miles apart.

In New Jersey the board and care industry includes both boarding homes, rooming houses and what we call residential health care facilities. According to regulation, the boarding home and residential health care facility provides virtually the same services and meals to residents. Rooming houses provide only shelter but no meals or services. Of the 10,000 residential health care facility residents, 50 percent are over age 75, 25 percent are over 85, one-half of the residents have a history of State or county psychiatric hospitalization, are chronically mentally ill and frequently require powerful psychotropic medication, and one-half of the residents' sole source of income is Supplemental Security Income because they are

disabled or elderly. There are about 3,200 people living in boarding homes and the residential profile is much the same, except they tend to be younger and the incidence of chronic mental illness is even greater. There are 17,000 people living in rooming houses which includes YW/MCAs and shelters. Little is known about who they are, their medical condition and impairments and their need for services, although nationally as many as one-third of the shelter population are thought to be mentally ill. They are the least inspected facilities.

In New Jersey a residential health care facility is supposed to provide a room, meals, personal services including laundry, 24-hour supervision, assistance with bathing and dressing, 12 minutes of nursing care per resident per week, medication monitoring, some transportation, referral to community agencies, maintenance of records, and budgeting and safekeeping of residents' funds; all for $15 per day for the 5,000 or so Supplemental Security Income recipients. Of that $15, $11 comes from the Federal Government and $4 from the State.

Boarding homes are supposed to provide the same room, meals and services to residents except for the limited on site nursing care, starting at $11 per day for the 1,600 residents receiving Supplemental Security Income and Social Security. Of that $11 per day, $10 comes from the Federal Government and $1 from the State. Residents of residential health care facilities and boarding homes receiving Supplemental Security Income are expected to take care of all of their personal needs including the purchase of clothing on $55 per month. The State share of Supplemental Security Income has not been increased in more than 10 years.

In New Jersey community service providers are suppose to identify resident needs and provide services but the funding to do so is always inadequate at best or non-existent. In fact, the system conspires against the delivery of many essential on-site services. The system's problems include restrictions on Medicaid and Medicare funds. If, for example, a community mental health center or clinic wanted to provide mental health services to a Medicaid recipient at the boarding home or residential health care facility, the center or clinic would not be reimbursed for the service. Neither would home health aides nor programs aimed at rehabilitation. Disabled persons who have a work history and receive Social Security disability are not even eligible for Medicare benefits for two years after they become disabled. People with work history are therefore treated as second class citizens and are entitled to less in medical benefits than if they had not worked at all.

The persons that own and manage these facilities are a mixed group. Some are conscientious, caring and excellent operators and run homes that I would live in myself, many are not. At present only a 40-hour training course is mandated in order to operate a facility which may have as few as two residents or more than 200. No testing is required. No professional or educational background is required. The quality of care ranges from excellent to poor and is usually proportionate to what you can afford to pay. Even the most conscientious well-intentioned operator, and there are many, can only do so much on the $11 or $15 per day per resident allowed for room, meals, laundry and a variety of other essential services. It is

no wonder that many operators most qualified to provide for these elderly and disabled residents would not go near the board and care industry.

I would like to make the following recommendations:

First, we must recognize that these residents are in need of long-term care just as in nursing homes although the nature of services may differ somewhat. To expect someone to purchase shelter, meals, and appropriate care on $11 or $15 per day, supported by only Supplemental Security Income or Social Security benefits, is impossible. Financing these facilities should be at levels linked to the realistic costs for appropriate care, shelter and meals through Medicare and Medicaid reimbursement. Development of professional standards of care minimum qualifications for operators and federal oversight as with nursing homes are requirements.

Secondly, many of these facilities are mini-institutions in the community, and by sheer numbers and concentration overwhelm the local communities resources and ability to cope. In some cities in New Jersey, the number of chronically mentally ill and disabled seniors living in local neighborhoods in the community rivals that of State psychiatric hospitals and large geriatric centers. From the residents' perspective, these large facilities are possibly the worst places for treatment and rehabilitation. Most clinicians agree that smaller group facilities, supervised apartment projects, supportive services in the home and other locations are far superior sites for treatment and long-term care. Yet Federal financing does little and in many cases excludes the cost of care for services delivered on site to residents and does little to support the cost of care at home. For example, if the mental health clinic or the community mental health center wanted to provide on-site services in a board and care facility under Medicaid and Medicare, they would not be reimbursed for such.

Again for persons qualifying for Social Security Disability, there is a two-year waiting period for Medicare. I would also ask you to talk to your local visiting nursing agency about their problems with reimbursement for in-home Medicare services or the last time they can remember receiving reimbursement for physical therapy, speech therapy or occupational therapy. In fact the Medicare system, in terms of reimbursement and denials, has become such a problem that many States have even funded legal services organizations to sue Medicare on behalf of the recipients. New Jersey has established such a program by special legislation and has recently awarded a contract to the Law Project to represent Medicare recipients. In Connecticut, their Legal Assistance to Medicare Patients program overturns 70% of the initial denials of rejected Medicare claims for patients in the community eligible only for Medicare. In New Jersey the Law Project reverses 85% of initial denials for Supplemental Security Income and Social Security. Any system for claim approvals that is wrong 70 to 85% of the time needs to be revamped. Of course the fall-out effect on the client is to severely reduce options for residential treatment in the home or other small sites while increasing reliance upon institutional type sites including nursing and board and care facilities.

Third, we must do as much as we can to allow and encourage the states to allocate as much money to community programs and

small residential treatment sites as possible. In New Jersey 70% or 190 million dollars of our state's mental health budget supports our 7 state hospitals and geriatric center which serves 6,000 patients per year. Only 30% or 80 million dollars supports our 120 community agencies which serve in excess of 100,000 clients per year. State institutions consume 70% of the mental health budget yet serve only 6% of the mentally ill who receive services. In New Jersey the federal government will not contribute to the cost of care for anyone in a state psychiatric hospital between the ages of 21 and 65—less than 10% of the costs of these facilities. Yet it would pay for such costs in local inpatient community hosptials. This strips our state's ability to finance services in more appropriate residential settings. Private insurance coverage for services and treatment for mentally ill is a disgrace and patently discriminatory. Limitations on the cost of care and lifetime limits for mental illness are far more restrictive than for other illnesses and exist in almost every policy of insurance. Such limitations should only be allowed if they could be supported by actuarial data.

Lastly, I would suggest that the federal government enforce its own laws that already exist. The Keys Amendment to the Social Security Act, 42 U.S.C. 1382e, requires states to identify group living facilities in which significant numbers of SSI recipients live, establish standards appropriate to the needs of the recipient and insure the enforcement of such standards. Additionally, the states were to certify compliance by the facilities with the standards to the Secretary of Health & Human Services. Unfortunately, as far as I am aware, many states have not even developed any standards nor has the Secretary of Health & Human Services provided any oversight or required the States' certifications. I would also add that the Keys Amendment be modified so that the sanctions under the law do not punish the Supplemental Security Income recipient and that a third independent party be responsible to determine if the standards are adequate and being complied with. Experience has shown me that state departments are not disinterested parties.

I thank you for the time and opportunity to testify and if I can be of any help to the committee in the future, please feel free to contact me.

The CHAIRMAN. David Lazarus, thank you very much for coming today.

Mr. FLORIO. I would just like to express our appreciation for the fine work that you have done and that the Community Health Project has done over the years.

Thank you very much for your participation.

Mr. LAZARUS. Thank you, Congressman.

The CHAIRMAN. Our next witness is Mrs. Lippold. Congressman Pepper, would you like to chair this panel?

Alice Lippold is a former resident of a board and care home in Washington, DC. How far is this home from this building?

Ms. LIPPOLD. I guess about seven miles.

The CHAIRMAN. It is in the District of Columbia.

Ms. LIPPOLD. Yes, sir.

The CHAIRMAN. Ms. Lippold, we look forward to your statement.

STATEMENT OF ALICE LIPPOLD, RESIDENT, BOARD AND CARE HOME, WASHINGTON, DC, ACCOMPANIED BY ANNE HART, LONG-TERM CARE OMBUDSMAN, WASHINGTON, DC

Ms. LIPPOLD. Good morning. My name is Alice Lippold. I am 68 years old and I live here in Washington. I came here to tell you about the horrible experience I had as a resident of a District—it was a rooming house, really.

For over three years and up until just several weeks ago, I lived at 3200 17th Street, N.W., an unlicensed rooming house and apartment. Ever since I moved there to live with my friend Katherine, we have had nothing but problems. From day one, the wall and the window in our small room leaked like a sieve. Whenever it rained it was a real mess.

Keeping warm was also a problem. One very cold winter a couple of years ago we had no heat. We nearly froze to death because the owner of the home refused to fix the heat. He said it was too expensive. Each winter we had heat off and on because the owner wouldn't pay the heating bills. We almost never had hot water. He saved money and we suffered.

On the other end of things, for the last several months at this place, there were no working refrigerators. We had to keep all our food on the window sill and it could go bad. Even when the refrigerator was working, it was often infested with roaches.

Roaches and mice were a big problem. They were everywhere. Hundreds of roaches covered our curtains. They crawled all over everything. With the mice our saving grace was Arabella the cat. She helped kill the mice in our room. The owner said that an exterminator would be too expensive.

Also this home was not safe. For months the front door was busted and we had no lock. Anyone could walk in and out and they did. Just recently, an elderly resident was robbed. Also, less than a year ago a woman resident, Yvonne, was found murdered. She had been beaten to death.

The owners of this unlicensed home are living very well off of all the money they got off of us. One of them lives in a quarter million dollar home, has three cars, a boat and a place at the beach.

I know many other unlicensed homes taking in the elderly and disabled just in our neighborhood. One friend of mine pays all but $55 of his income to an owner. All he is getting is bologna sandwiches, and no real meals.

We would be living there today if it had not been for the good work of Congressman Claude Pepper and others. Investigators from his office came and found us living in these conditions. We are now temporarily living in a shelter for the abused elderly.

I hope that you all can do something to help people in my situation. We need to crack down on the greedy and uncaring owners.

Thank you very much.

The CHAIRMAN. Thank you, Mrs. Lippold.

Our next witness this morning is Mr. John Sharp. Mr. Sharp is a resident of a board and care home in Sacramento, California. Mr. Sharp.

We will allow the panel of witnesses to make their statements and questions will follow.

Thank you, Mr. Sharp.

STATEMENT OF JOHN SHARP, RESIDENT, BOARD AND CARE HOME, SACRAMENTO, CA

Mr. SHARP. Good morning. My name is John Sharp and I'm 64 years old. I've come here today because I used to live in the board and care home that received so much attention last November—the one run by Dorothea Puente. As you will recall, she is charged with burying the bodies of seven residents in the yard of her home and taking their benefit checks. I was living there at the time of Ms. Puente's arrest and I'm here today because I am one of the few survivors of her form of care.

I moved into the Puente board and care home, at 1426 "F" Street in Sacramento, January 12, 1988. Before that I lived at the Salvation Army Men's Shelter. The reason I live in board and care homes is because I can't afford anything else. Because of severe back injuries, I am permanently disabled. I've been receiving Social Security disability benefits and Supplemental Security Income since 1987. My total monthly income adds up to $675.

I often wonder why I was spared from a terrible fate at the Puente home. I didn't turn over my Social Security checks to her and, looking back, that's probably what saved my life.

When I moved into the home, there were two other men living there. When these left, others would come and take their place. They ranged in age from 60 to their late 70s.

There was never very much going on at the Puente boarding home. Most of us stayed around the house all day because there was nothing else to do. There was never any staff around to do anything, like give you a ride to the doctor or something, or to help out some of the sicker residents. Even if you just needed to get some aspirin, or have a prescription filled at the drug store, there wasn't any way to manage it. Except for when we got the meals, there was really no service provided to us at all.

While I was living at Ms. Puente's home, I noticed many strange things. First, one day I discovered her going through some residents' mail. She looked startled when she saw me. Another time I saw her opening the mail of people who no longer lived at the house. She explained that one to me by saying it was a routine procedure. She opened the mail for seven residents who had moved out but still used her address. She liked to help these folks out by cashing their checks. When she saw them again, she would give them the cash. The whole time I was living in the house, I never saw her give anyone their money except Burt Montoya. She gave him a dollar or two every now and then but certainly no large amounts.

The second strange thing I noticed was the mysterious disappearance of residents. I asked Ms. Puente where everybody had gone and she told me not to worry. She had kicked several of them out because they hadn't paid rent she said. Others had simply moved on. I couldn't buy her story because one thing wasn't right. These people, who I lived with every day, hadn't come to tell me good bye. That didn't fit. Sure, some of them kept to themselves, but they would have had the courtesy to say something to me before

they left. But, because I had no other place to live, I didn't ask her any more questions.

I know the newspapers have said that Ms. Puente probably poisoned the poor victims who were buried in her yard. Looking back, I remember she was very insistent about people taking their medicine. She told Burt to take his pills on many occasions.

One time, Ms. Puente asked me if I would allow her to receive and cash my Social Security and SSI checks. She said she did it for others and found that it worked out well for everyone—saved them from unnecessary hassle. I told her that those checks were my lifeline and I couldn't trust them to anyone but myself. I'm sorry, but that's the way it had to be.

Where I live now is a better home than Ms. Puente's. It is only a single-family home and I just rent a room there. I am the only boarder.

Sometimes I think how lucky I am to have gotten out of the Puente house alive. But I worry, too, that in the future, I might get sicker and need a facility that provides more medical care and I'm sure I won't be able to afford it.

Board and care is the only answer for a lot of people. I hope you Congressmen can figure out a way to keep those homes safe. They should be a good place to live—not some deathtrap.

Thank you.

The CHAIRMAN. Mr. John Sharp, we thank you.

We will have a few questions in a moment.

Mrs. Ring, if I might ask you this: could we skip over you at this moment to Julie Oetting, because Senator Shelby, of Alabama, has a committee meeting that he must attend in a few moments and I think he would like to say something about his constituent, Julie Oetting.

STATEMENT OF SENATOR RICHARD SHELBY

Senator SHELBY. I appreciate your courtesy in doing this. I have to go preside over the Senate at 11:00 a.m. and it is something that we have to keep doing. I didn't want to miss my Alabamian's testimony here today. I believe she has got a lot to contribute.

Thank you, Mr. Chairman.

[The prepared statement of Senator Shelby follows:]

RICHARD SHELBY
ALABAMA

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SENATOR RICHARD SHELBY

Statement for the Record

Board and Care: A Failure in Public Policy

March 9, 1989

Mr. Chairman, I would like to commend you for holding this very important hearing today. Over the February recess, I held a series of town meetings in my home state of Alabama and one of the concerns expressed repeatedly was the need to address the problems associated with long-term illness. Many elderly citizens are worried about the cost and availability of quality health care should they or a family member be stricken with a chronic illness.

Today's hearing on Board and Care is very timely for it addresses these concerns raised not only by my constituents, but I am sure by seniors across the country.

"Board and Care" is the catchall phrase used to describe facilities which provide residents room, meals, and some type of assistance or oversight. These board and care homes include group homes, foster homes, adult homes, personal care homes and rest homes and provide many elderly and disabled adults with housing, meals and care that they may be unable to receive elsewhere. However, we must ensure that these residents receive safe and clean housing, nutritional meals, and quality care.

Residents in these homes are often our society's most vulnerable citizens -- they tend to have some physical limitation, low income, and have often lived in some mental institution due to a mental disability. Residents are also unlikely to have many visitors on a regular basis. Thus, it is imperative that there be some mechanism in place to assure that these board and care residents receive proper attention.

According to the study released today by the General Accounting Office, the total number of board and care homes in operation in the United States is unknown. This poses a problem in any attempt to evaluate the care given in board and care homes and to address the needs of individuals living in these homes. In 1987, an industry association conducted a survey of state regulatory agencies and found 41,000 licensed board and care homes in operation.

However, the authors of the survey stated that its information was incomplete due to variances in board and care definitions, and the fact that some states are just beginning to license these facilities. There is also some confusion over the difference between board and care homes and boarding homes, thus further making estimates difficult. This figure is especially low, given estimates that there exist at least as many unlicensed board and care homes in operation as those which have obtained a license.

I am particularly concerned about the quality of care the residents in board and care homes receive. The GAO study cited serious problems which states have found through their inspection process or in response to complaints. These horror stories include sexual and physical abuse of the residents, lack of medical attention, unsanitary living conditions, lack of heat in the homes, and many others. The GAO found that these problems are especially acute and concentrated in homes with predominately low-income residents (especially those residents dependent upon Supplemental Security Income payments).

This situation is unacceptable. We must ensure that our elderly and disabled citizens do not fall prey to such insidious abuse and neglect. I do not mean to malign all board and care homes. For as I stated earlier, board and care homes can provide a practical alternative to more costly institutional care. This beneficial role may only increase with the recent implementation of a provision in the Omnibus Budget Reconciliation Act of 1987 which prohibits nursing homes that receive federal funds from receiving mentally ill or retarded individuals unless the state mental health authority has determined this person needs nursing home care.

Mr. Chairman, I believe that we must determine the proper role the federal government, states and board and care providers should play in this debate. I think we all agree that the health and safety of our elderly citizens is our prime objective. I look forward to hearing from our panels of distinguished witnesses this morning to gain their insight on this matter. I would like to extend a special welcome to Ms. Julie Oetting, an ombudsman working in Jefferson County, Alabama. Thank you Mr. Chairman.

STATEMENT OF JULIE OETTING, LONG-TERM CARE OMBUDSMAN, JEFFERSON COUNTY, AL

Ms. OETTING. Good morning, Mr. Chairman and members of the committee. My name is Julie Oetting and I am the Long-Term Care Ombudsman for Birmingham, Alabama, in Jefferson County.

I'm pleased to be here to talk to you about a subject that has become very important to me both professionally and personally—the problems of board and care homes in Alabama. These homes have become a major housing option for the elderly and mentally ill, a very vulnerable population. While many of these homes are operated by owners motivated by a desire to help, unfortunately, there are also many which are operated by those who prey on the misfortune and vulnerability of others.

Over the past two years, I have seen too many cases of poor care, neglect, starvation, abuse, financial exploitation of SSI and Social Security checks and deprivation of civil rights. Some examples of the conditions recently found in Alabama include:

First, two elderly women were sent to the hospital from a boarding home, covered with gangrene-infested bedsores, and were suffering from severe malnutrition and dehydration. Both women, aged 85, died in the hospital shortly after admission. Of the five residents in this home, three suffered from malnutrition.

Second, during an investigation in a licensed boarding home, I found 11 people with nothing to eat but a small jar of peanut butter. The home was dirty, infested with roaches, had holes in the walls, smelled horribly of urine, had no privacy of bathroom facilities and an untrained housekeeper was found to be illegally giving insulin shots.

Third, a resident was assaulted by the home operator. She secretly taped a conversation where the operator admitted to abusing residents and to have killed a woman. I would like for you to hear excerpts from this tape.

The CHAIRMAN. The tape is ready to be played at this time. Before the tape is played—this is a tape, as I and Congressman Pepper understand, is a transcript between a board and care home operator and a board and care home resident. This is correct?

Ms. OETTING. Correct.

The CHAIRMAN. Without objection, the actual transcript of this tape will be inserted at this point in the record. It was a little hard to hear, but the transcript is pretty plain.

[The transcript of the tape follows:]

TRANSCRIPT OF TAPED INTERCHANGE BETWEEN AN ALABAMA BOARD AND CARE RESIDENT AND OPERATOR**

Board and Care Home Operator:	You've got to learn one thing and you have the common sense to know it. You done went all over the world being mean to other people. That's just not right.
Board and Care Home Resident:	It's not right to lie either.
Operator:	Yea! I will tell anything to get my point across to the people that are going to handle you.
Resident:	Even lie?
Operator:	Yea, and I would do it to anybody in this house.
Resident:	It is alright to slap somebody around and lie about it?
Operator (Screaming):	If you ask for it, you get it!
(BREAK)	
Resident:	You really shot a woman for pulling your wig off?
Operator:	Yes.
Resident:	I can't believe you would do a thing like that.
Operator:	Is that right?
Resident:	So you killed a lady just because she pulled off your wig?
Operator:	Let me explain, we were fighting, she pulled off my wig. I come home the next day, I went back and throwed chlorox in her face and shot her.
Resident:	You shot her?
Operator:	Yea.
(BREAK)	
Resident:	I don't believe that you slapped me.
Operator:	Well, I got mad.
Resident:	You can't slap someone just because you get mad.
Operator (Screaming):	Yes you can. You know that you are not suppose to cuss in here. See Mary, this is a domiciliary (board and care home).

** The operator recorded here is a convicted murderer.

The CHAIRMAN. Ms. Oetting.

Ms. OETTING. Thank you.

An investigation found that this operator was indeed a convicted murderer. Current investigations have found that this operator has repeatedly physically and financially abused residents. She also has life insurance policies on boarders. Despite all of this, this woman continues to operate board and care homes and legally at that.

In Alabama we have 3 levels of care:

First, Boarding Homes—licensed only in Jefferson County to provide room and board to those individuals who are independent of all personal care needs. Jefferson County Health Department has 84 licensed boarding homes and 73 mental health homes. Statewide there are no regulations and most homes are unaccounted for.

Second, Domiciliary Care Homes are personal care homes licensed by the State Health Department.

Third, Nursing Homes licensed by State Health Department for skilled and intermediate nursing care.

Fourth, The State Department of Mental Health has oversight of homes that are actually boarding homes and domiciliaries for Mental Health clients. These homes do not fall under the jurisdiction of the State Health Department; therefore there is no monitoring of the mental health system.

Inappropriate placement of residents is a rampant problem in Alabama. This summer a survey was done by a public health nurse in 77 Jefferson County boarding homes. At least 25 percent of the 420 individuals assessed needed a higher level of care. The nurse rated 51 of the 77 licensed homes as substandard. The nurse found residents being fed through tubes, residents with catheters, bed sores, severely confused, unable to take their medications, and many in need of urgent nursing and other types of care. She also found residents physically restrained to beds and chairs, just as I have on my visits. I had to confiscate these restraints when some staff from Congressman Pepper's office were visiting some of our homes.

A local fire inspector visited 40 homes. He found that 35 of the 40 homes did not even meet minimum standards due to structural problems and the physical condition of the residents.

Over the past year a great deal has been done in Birmingham to improve our board and care homes. A consortium of community leaders from agencies such as the Area Agency on Aging, Public Health, the fire and police departments, the Adult Protective Service Agency, the Mental Health Authority and the local media met to discuss these problems and develop a plan of action. The results of this inter-agency networking included:

First, the strengthening of our county boarding home regulations. The new regulations, passed on January 11, 1989, include requirements for residency, a residents' bill of rights and minimum standards for room furnishings. The old regulations focused only on "brick and mortar" requirements.

Second, approximately 75 percent of the elderly and disabled residents who have been assessed as needing more care were moved to appropriate facilities, including nursing homes and domiciliaries.

Third, due to increased media attention to the problems, there has been an increase in public awareness of the problems of boarding homes. Last month the Health Department and ombudsman received 15 complaints of illegal boarding homes reported by people in the community.

Fourth, free in-service education programs are being provided to home operators and social service providers.

Fifth, there is an advocacy effort to bring about better adult abuse laws and Statewide boarding home regulations, much like Jefferson County's, that would also allow background and character checks of operators.

Sixth, agencies are working with many of our good boarding homes who have formed a Quality Boarding Home Association where they plan to police each other. We are working with them to develop policies such as financial contracts with their boarders and ideas such as "co-op food buying."

While we have made a great deal of progress through the hard work and cooperation of many, the problems which still exist in Alabama include:

One, operators with criminal backgrounds are still operating homes.

Two, abuse and neglect of residents still exists. For example, in December ten elderly people were found at night in a cold, damp, urine-smelling basement. One lady died several days later, she had a half a dozen bedsores—some of them 4 inches long.

Three, there is no real oversight of Social Security and SSI checks. Anyone can become a payee for any number of checks. We continue to have many cases of operators keeping individuals' checks when they move to another location.

Four, surrounding counties have absolutely no regulations for boarding homes. So, bad operators in our county can just move to the next county without any regulatory oversight.

What do we need to solve these problems? Aggressive Statewide and Federal regulations, better adult abuse laws, an increase in SSI and Medicaid benefits, an adequately trained social service network for the elderly and mentally ill, and educational programs for facility operators.

Thank you for your time.

The CHAIRMAN. Thank you very much, Ms. Oetting. I think you have a Congressman friend here who wants to make a statement. Mr. Erdreich.

STATEMENT OF CONGRESSMAN BEN ERDREICH

Mr. ERDREICH. Thank you, Mr. Chairman.

I'm delighted that Julie Oetting could be here. As you have heard, Mr. Chairman, her testimony is very moving and to the point. She is the ombudsman of the Office of Senior Citizen Activities of Jefferson County, Alabama, which I have the privilege to represent. It is with special pride because it is an office that I started as a county commissioner in my earlier incarnation some 13 years ago in 1976. It's still going strong and indicative of the ombudsman's role. It is something under the Older Americans Act that is providing a major service in our community.

I would add that the focus of these hearings, Mr. Chairman, and some excellent investigative reporting in our local newspapers that did a series on boarding home problems, the focus of our State has been riveted on this problem and I think we're getting some State action.

Again, I would like to complement the chairman for these hearings and Julia, I welcome you to Washington and your testimony was excellent. Thank you very much.

The CHAIRMAN. Thank you very much.

Senator SHELBY. Again, Mr. Chairman, thank you for your courtesy.

The CHAIRMAN. Thank you, Senator Shelby.

We will now call on Mrs. Ring and then we will open for questions.

Mrs. Ring, thank you for letting us pass you by a moment ago. We appreciate that very much.

STATEMENT OF IMA RING, INDIANAPOLIS, IN

Mrs. RING. I'm Mrs. Ima Ring from Indianapolis, Indiana. Good morning.

I came here this morning to tell you about the terrible problems my deceased brother had as a resident of a board and care home in Michigan.

My brother, Fay Garner, was 72 years old and was living at his lifetime home which he loved in Niles, Michigan. He retired after many years as a factory worker with Standard Products. He was suffering from cancer. In May of 1987, Fay had a terrible attack of pain from his cancer. He called an ambulance to take him to the hospital, where he could be checked by a doctor. Much to his shock, the ambulance took him not to the hospital, but to a board and care home. Apparently, a doctor had prescribed this place and put him there.

Shortly after Fay was put in the Lilac Manor Foster Care Home, my daughter and I drove from Indiana to see him. We got there to the home, which was a big old house, and the owner and operator chewed us out. She screamed and yelled at us and was just hysterical. She said, "How dare you come to this house without an appointment?" She said that nobody could visit without making an appointment in advance. We were scared but we went on in anyway to see Fay. What we saw was not a pretty sight. My daughter asked me which one was her uncle—he looked that different. He was wet in his own urine and had lost so much weight it was pathetic. The staff said that he wouldn't eat; however, he ate like there was no tomorrow when my daughter went and bought food and brought it in and when I would bring him food.

Another time when I went to visit my brother, it was over 100 degrees outside. It was just terrible. Fay was obviously suffering from extreme heat. There was no fan, no air conditioning in his room. The only source of air was a cracked window. It had no screen to keep out the bugs. The home operator didn't seem to care. She told me; "This is my house and I take care of these people the way I want to."

On another occasion, a friend of mine found my brother lying on the floor. When questioned about his being on the floor an aide said, "He likes to lay there and watch TV." Well, my brother never laid on the floor before in his life. He had fallen or had been pushed and was too weak to get up without help.

This place was not cheap, either. My brother paid over $1,400 a month for the privilege of being abused and neglected. That didn't include the cost of anything else like drugs and personal items. It seemed that the owner was after my brother's money and the heck with anything else.

I always found him thirsty. There was never a pitcher of water where he could get to it. I asked the operator why there was no water at night. She said they wouldn't give him water after 8:00 p.m. because of bed-wetting.

After being in this home for several months, my brother was rushed to the hospital by ambulance. He arrived unconscious and nearly dead. His lungs were infected and his kidneys had stopped functioning. He was severely dehydrated. The doctors at the hospital said he was so severely dehydrated, it was the worst case they had ever seen. In addition, Fay was literally covered with bruises and bedsores—he had either fallen or been beaten. The doctors and the nurses at the hospital said that my brother had been severely neglected. They also said that they had at least three other patients who'd been admitted from Lilac Manor.

Fay was in the hospital for three weeks. I demanded that they put him only in a qualified nursing home when he was released. He died after one week in the home, which was a good place. My family all strongly believe that the neglect he suffered at Lilac Manor resulted in his premature death. It just breaks my heart that his last days were such a disgrace and that he had to live in a place so far removed from where he so badly wanted to be—in his own home.

It was too bad for my brother. I came here today to save the lives and dignity of others. Please do what needs to be done to prevent this home from continuing to hurt vulnerable people like him.

Thank you.

The CHAIRMAN. Mrs. Ring, thank you. Not only for your statement but your contribution.

We will now hear from Anne Hart, the Long-Term Care Ombudsman for the District of Columbia.

STATEMENT OF ANNE HART, LONG-TERM CARE OMBUDSMAN, WASHINGTON, DC

Ms. HART. The program in the District is funded in part by the D.C. Office on Aging but it is located in the Legal Services Office at Legal Counsel to the Elderly, which is a legal services office serving low-income older persons in the District of Columbia.

Legal Counsel for the Elderly is also sponsored by the D.C. Office on Aging and the American Association of Retired Persons. My testimony here this morning is given in my capacity as the ombudsman and is not necessarily the position of the American Association of Retired Persons.

We didn't really start to focus our advocacy efforts on residents of board and care homes until 1987, when we received an increase in our funding which allowed us to hire a full-time staff person to investigate complaints about the board and care homes in the District and advocate on behalf of the approximately 2,000 board and care home residents.

We have about 250 licensed board and care homes in this city. Most of them are in small private homes. They are run like mom and pop rooming houses and are generally created by using bedrooms in existing houses. They are generally operated by older women. The average size is from six to eight residents, although there are several facilities in the city with more than 30 residents and we have one that houses more than 150.

We have received hundreds of complaints about board and care homes. Here is a sample:

A husband called me to say that his wife, who is confused and lives in a board and care home, had been tied down with rope and now had burns on her wrists and ankles that resembled a torture victim's wounds.

A grandson called to say that his grandmother was missing from an unlicensed board and care home. The home said that the resident was taken by ambulance to an area hospital but neither the ambulance nor the hospital had any record of the missing grandmother. Later, the grandson discovered that his grandmother had become a Jane Doe cadaver used for teaching purposes at a local hospital.

Four female residents alleged that their board and care home director had repeatedly sexually abused them demanding oral sex and intercourse for himself and his friend in exchange for 20 cents, 60 cents, and a can of beer.

A board and care home director charges residents in this city for toilet paper and charges them for watching television.

Residents of a licensed board and care home beg at neighbors' houses for extra food. A neighbor reports that residents who come to her door begging for food are so hungry that they stuff the food in their mouths before they even leave her front porch.

A resident's family reported that a licensed board and care home director took thousands of dollars from the resident's bank account.

A resident died of an impacted bowel, which is a very treatable condition, after the licensed board and care home failed to detect noticeable deterioration in the resident and failed to obtain necessary medical care.

When we visited some board and care homes in the District with some of your staff, Congressman Pepper, we happened to choose a licensed facility where the only staff member on duty was intoxicated. We witnessed her verbally and physically threatening the residents when they asked for more food.

There are many board and care homes in this city that are providing decent, humane care for residents and we are very sympathetic to their concerns. They serve those residents without the benefit of much training and for pay that is way below the minimum wage. For example, board and care homes in the District are only paid $15 a day or 60 cents per hour for their service.

We have also identified a number of unlicensed board and care homes. For example, last summer, I received a call from a hospital emergency room social worker who described admitting an elderly woman who was covered with feces, smelling of urine, her stockings were so dirty that they had actually bonded to her legs, and her feet were infested with live maggots.

The social worker recalled that another elderly resident from the same address had been brought to the hospital less than two months earlier who was also suffering from dehydration, malnutrition, smelling of body wastes and covered with infected bedsores.

Our investigation revealed that both of these elderly people were residents of an unlicensed board and care home that housed nine other elderly people in squalid conditions. Everything was covered with a thick film of dust, there were cobwebs three feet across, nine inches long hanging from the ceilings and winding around chair legs. The electrical wiring was exposed. Residents were served rancid food. Even a bushel of potatoes was breeding flies and maggots. There was no hot water.

Our investigation revealed that at least three different D.C. Government agencies—the licensing agency, the adult abuse agency, and the Mental Health Commission—all had been aware and documented these conditions for years.

Several of the residents who were living in this home even had Government caseworkers who visited them on a regular basis.

We have a model law in the District of Columbia that covers boarding homes and nursing homes. It authorizes me as the Long-Term Care Ombudsman, as well as private citizens, to seek a receivership if and when the Government fails to take action. Because of this law, we were able to file suit against the owner/operator of this unlicensed facility. We were able to take action in a situation because D.C. law provides for a private right of action and because there was legal support available to the ombudsman program. The law itself provides important rights but it is equally important that ombudsman programs have linkages with legal services agencies so that there can be the legal support necessary to enforce these rights.

The major recommendation that I would make to you, speaking as the Long-Term Care Ombudsman and not as a representative of the American Association of Retired Persons, is that similar provisions such as the private right of action, receivership and mandated standing for the ombudsmen to actually sue be included in any of your residents' rights laws.

It is not simply enough to require that there be regulations or that board and care homes be inspected or that residents be given case managers, or even that the ombudsman program be given additional funding to visit board and care facilities. These are simply not enough. In 1987 amendments to the Older Americans Act required that States ensure adequate legal support to the ombudsman program. This means zealous advocacy. The District recently enacted ombudsman enabling legislation which provides the model for implementing this type of advocacy.

Board and care homes in the District are required to be licensed to operate and they are inspected by the Government at least once a year, but it has been very difficult for advocates and families to

get copies of the inspection reports. Any legislation that these committees consider should include liberal public access to these inspection reports.

We've passed many strong laws in the District that give the regulatory agency a range of options to use against substandard homes. These include provisional licenses, a ban on admissions, appointment of a monitor or a receiver and a fining system for violations of specific regulations. We keep asking ourselves then why are conditions in some of the board and care homes in the city so bad. In some cases, it is very difficult to get the regulatory agency to act. In other cases, it is difficult to get enforcement handled consistently. Fines are often issued for purely superficial paperwork violations. Our experience is that the Government simply does not have sufficient resources to address every serious problem in board and care homes. We need legislation, not only for tightening licensing requirements, but also to create intermediate sanctions and also legislation for a private right of action that mandates legal services support for the ombudsman in monitoring these board and care homes.

Thank you.

The CHAIRMAN. Thank you very much, Ms. Hart.

I think Congressman Pepper now has questions.

Ms. HART. All right.

Mr. PEPPER. I would like to ask Ms. Hart, is the District of Columbia licensing all these board and care homes?

Ms. HART. There are required to be licensed if there are one or more unrelated people living in the house that are there for social, familial or financial reasons. Yes.

Mr. PEPPER. The District of Columbia Government inspects these homes to see what kind of care is being given these people?

Ms. HART. Yes, sir.

Mr. PEPPER. How did they fail to observe the conditions that my representatives and you found there?

Ms. HART. It became a bureaucratic circle. It was a problem of definitions. They were saying that it was not a boarding home because the residents there wanted to be there. It became a big argument about what is board and care. I think that has been raised earlier about all the different names for it and the different things that it is called in different States and how we define it so that we can get a handle on where they are and start regulating them.

Mr. PEPPER. Do you report any findings that you make to the District of Columbia Government?

Ms. HART. Yes, every month.

Mr. PEPPER. Are they doing anything about it?

Ms. HART. They are beginning to.

Mr. PEPPER. They are beginning to.

Ms. HART. Yes, sir.

Mr. PEPPER. Have you appeared before or contacted any members of the District of Columbia Committee to tell that committee about the conditions you find?

Ms. HART. Yes. I regularly appear before the City Council on these issues. As I said, they did pass the Ombudsman Enabling Law that give the ombudsman program similar authorities as the licensing agencies. There are, however, proposed regulations in the

District that would allow boarding homes to start admitting residents who are incompetent, who are need of continuous nursing care—again, it's an effort to save money. Nursing home care in the District costs easily $45,000 a year and as I said the boarding homes are getting $15 a day. That's a big savings in money.

Mr. PEPPER. Did you say that the amount that these homes are receiving for each patient is $15 a day?

Ms. HART. Yes, sir.

Mr. PEPPER. That's not enough to authorize proper care for them, is it?

Ms. HART. No and, I think more importantly, it is not enough to pay them in order for us to get a handle on making sure that they are provided good quality. It's like what do we expect if we're paying them $15 a day, it's not surprising that we have these problems.

Mr. PEPPER. Do you think it would be helpful if these people were allowed to continue to receive the benefits that they received before they went into these homes?

Ms. HART. Yes, sir, I do.

Mr. PEPPER. The additional contribution——

Ms. HART. At least that much if not more.

Mr. PEPPER. The $15 a day requirement is a part of the law now, isn't it?

Ms. HART. That is what the boarding homes in the District get paid. That includes the State supplement that is given to them in the city.

Mr. PEPPER. Mr. Chairman, I think we need to contact the District of Columbia Committee in the House and Senate and see if they can't look into this situation.

I have just one other question of Mr. Sharp here. Mr. Sharp, living in this home in Sacramento where the lady was accused of killing seven of the inmates—did you all suspect anything foul going on in that place?

Mr. SHARP. I did after a certain length of time. Not right at first. One of the gentlemen came up—he was pretty much of a drunk, an alcoholic——

Mr. PEPPER. How did she kill the people, by drugging them?

Mr. SHARP. That's what they say. I don't know. I don't believe they have reached any conclusion about it.

Mr. PEPPER. And you didn't hear anything about people dying in the home?

Mr. SHARP. Yes, I did. Actually, Dorothea told me about one of the cases, but she didn't state it as fact. Although I think it turned out to be fact later on.

Mr. PEPPER. I am advised that she continued to cash the Social Security checks of these victims a good while after they had been killed.

Mr. SHARP. Yes, sir. She was still cashing—she told me she was taking in seven checks a month and cashing them. That was right up until the time that they arrested her.

Mr. PEPPER. Do you think our recommendation that it would be desirable for the Social Security Administration to follow up as best it can when somebody other than the proper recipient receives a Social Security check?

Mr. SHARP. Yes, sir, I believe so.

Mr. PEPPER. Thank you very much, Mr. Chairman.

The CHAIRMAN. Thank you, Mr. Chairman.

I think there was some very relevant testimony given a moment ago by Ms. Oetting and I would like to ask David Lazarus and Anne Hart this question. Ms. Oetting testified that she had found in her State investigations a number of insurance policies made payable to the owner and operator of the boarding home facility. Now, are you finding this in the District? Are we finding this also in New Jersey?

Ms. HART. We have not found that in the District. I think in part because we have been summarily denied access to a lot of the records that we made to make our investigations.

The CHAIRMAN. That leads me to a second question and then we will go back to insurance. Do ombudsmen have the absolute right to enter a boarding facility at any time—day or not and no matter what day? Do you have that authority?

Ms. HART. As a result of the enabling legislation I just mentioned to you, I will on the 15th of March of this year.

The CHAIRMAN. But only in the District of Columbia.

Ms. HART. Right.

The CHAIRMAN. This is not true out in the rest of the country, am I correct?

Julie, would you or David Lazarus like to respond?

Ms. OETTING. In Alabama, we have access during visiting hours or normal operating hours.

The CHAIRMAN. I have found in my past years of looking at some of the nursing home conditions that during the visiting hours that's when most of the staff is on duty. It's from dusk until dawn when many, many of the atrocities occur and the horror stories result. Mr. Lazarus?

Mr. LAZARUS. As to the insurance question, I have not found that. However, there is a situation analogous to that in that many, many boarding home operators are the representative payees on Social Security benefits. They can basically cash their check with or without the authorization of the recipient.

The CHAIRMAN. In Alabama, New Jersey, and the District of Columbia is there any checks and balance system in force that enables us to see if the person operating a particular facility has a criminal record?

Mr. LAZARUS. It's funny that you ask that specific question. In New Jersey, supposedly, a convicted felon is not supposed to operate a home. However, we had a case of an 86-year-old woman who turned over her entire life savings of $32,000 to a board and care operator, plus her monthly Social Security check, for a life-time tenancy. Two years later she was being thrown out. When we tracked down the operator and checked, we found that he had several felony convictions. He had been imprisoned in Danbury Federal Penitentiary where he had met the previous owner of the facility and he is still operating that facility today despite our reports to the State agency responsible. I do not necessarily want to indict the State agencies, I think they have a very difficult job and there are a lot of places to inspect with only a handful of inspectors. I don't

want to do that, but I am trying to answer your question truthfully, sir.

The CHAIRMAN. Thank you, sir.

Any other comments to follow there, Ms. Oetting or Ms. Hart?

Senator Heinz.

Senator HEINZ. Let me also announce for my colleagues, I have just been informed that at 4:00 p.m. this afternoon there will be a vote on the Senate floor on the nomination of John Tower.

Mr. PEPPER. At what time?

Senator HEINZ. At 4:00 p.m. this afternoon.

First, let me thank all of you for coming here today. It's not easy to listen to some of the stories that you have told and it must be even worse to have lived through or seen them yourself. I remember my first visit to a boarding home back in 1971 when Senator Pryor was then a retiring Congressman. He was running for the Senate. Congressman Pepper referred to that age, 20 years ago, when he was attempting to establish the House Select Committee on Aging. A small footnote is that when David Pryor left, I asked him if I could take up that battle to form the House Select Committee on Aging and it was subsequently my legislation that passed to do that. So, Senator Pryor and Congressman Pepper and I go back a long, long way and Congressman Pepper and I intend to introduce legislation incorporating many of your suggestions in the very near future. We will call it probably the Pepper-Heinz bill because if it is called the Heinz-Pepper Bill it would be thought to be too commercial.

I would particularly like to address my question to the ombudsmen, Mr. Lazarus, Ms. Oetting and Ms. Hart. My question is this: in your experience, have you seen homes that have been providing, if not luxury, at least adequate care? Have you come across fairly well run establishments?

Ms. Oetting.

Ms. OETTING. Yes, we have. We have some very caring, compassionate operators that do a good job. We have also got some operators that would do a good job if they knew how but they are not capable.

Senator HEINZ. Mr. Lazarus, is that generally the case in New Jersey?

Mr. LAZARUS. Yes. There are homes that we have visited and I am familiar with that I would be happy to live in myself or place my mother there if need be. However, we're talking about private pay homes, Senator. Basically, the rule is you get what you pay for.

Senator HEINZ. Have you encountered any homes which have fairly poor largely SSI dependent residents which none the less do a reasonably good job?

Mr. LAZARUS. Yes. Absolutely. There are——

Senator HEINZ. As opposed to those where you have a higher level of income?

Mr. LAZARUS. Yes. Absolutely. That's, if I just may add something, sir, we're talking about people basically without any educational experience, without——

Senator HEINZ. You anticipate my question. Your point is well taken. My question is simply this: what seems to be the difference between the relatively well-run board and care home with relative-

ly poor residents v. the badly-run one? It is a question as you started to say of education, know-how, training?

Mr. LAZARUS. Absolutely—nursing presence in the home—but also if I may add particularly in New Jersey and across the country, a good number of individuals that reside in these homes are chronically mentally ill. Even in the good homes, outside of maybe nursing care, there is very little and in some instances virtually none with no rehabilitation services going on within the home. Nothing happening from the outside. Although in New Jersey they have made an attempt to do that. But there is very little funds and very little money out there to bring the agencies in.

Senator HEINZ. Understood.

Ms. Hart, what is your experience? Is there the same kind of spread? I don't want to bias the assessment by asking are there upper-income homes that are good—I'm trying to look at each strata.

Ms. HART. The ones that are receiving SSI—there are some that are very good in this city.

Senator HEINZ. In your experience it is the same. It has to do with the know-how, the background, the training, the education of the providers.

Ms. HART. And the commitment.

Senator HEINZ. Yes.

Does that imply that if we knew how to urge the providers at all levels to improve themselves, that they could? Or are there too many people in the industry who just, no matter what you did, whether carrots or sticks, to become better, that they wouldn't for one reason or another. Which is it, Ms. Hart? Is there hope for elevating this industry? Is it generally well meaning people?

Ms. HART. Yes, I believe that. I think to add to your list, we have to start paying them an adequate wage.

Senator HEINZ. How do the people who provide good care in the facilities for private housing and caring for low income people—how can they get by if their financial rewards are basically no different than others?

Ms. HART. I would answer that by saying that the places that I am describing that are good are operated much more like a family. They are in small houses, they are small places, and the whole feeling in them is as a family. The residents, generally, have lived there a long time and they are sort of adopted. I would say the answer is the same way that a large family manages to get by.

Senator HEINZ. What about the homes in your States that are good that have a predominantly low income population? What seems to set them apart from other homes in similar financial circumstances?

Mr. LAZARUS. I think it is a question of caring, commitment and on-site supervision. We have the homes that tend to be the better ones even with surviving on an SSI rate are that do this as a cottage industry so to speak. These are smaller homes that take people in as referred to as part of a family. That doesn't mean that is anywhere approaching what the level of appropriate care would be.

Senator HEINZ. Let me ask one last question. I suspect my time is probably running out. The Chairman is awfully kind. He has let

me be the chairman of the committee for a while. Let's assume that, in fact and I don't know what judgment we will eventually come to, there is too low a level of transfer payments or fees for services taking place here overall. We can get some improvements in the industry to provide assistance but not enough. Let's assume that. There are at least two ways from a Federal level we could do that. One is to increase SSI. The alternative is to make direct payments to providers of care for specific care delivery. Which, if you had to choose between those two, would be a better methodology.

Ms. HART. I would say the one that has stronger protections on it. The one that would include more oversight, more on-site monitoring, and more of a system so that we know if there is exploitation there.

Senator HEINZ. Which of those would that be?

Ms. HART. I'm not sure. It would depend on how they are set up.

Senator HEINZ. I was making an assumption. My assumption is that we will pass legislation that will provide for meaningful licensing, standards, training, oversight, ombudsmen rights, shared public access to records, maybe a private right of action and some of the protections you were talking about—a layer of protections. Having set up all of the protections we can, then the question is: maybe that doesn't do the job if there are two ways of providing more resources either to the residents through SSI or in some kind of case management basis through vendor payments. Which, if we have to choose between doing one or the other, should we choose. Anybody else want to take that?

Mr. LAZARUS. May I comment on that?

Senator HEINZ. Yes, Mr. Lazarus.

Mr. LAZARUS. In my mind, increasing the SSI rate is at least in part not the answer. Even if Congress was to pass laws and safeguards which we already have on paper in New Jersey, it still does nothing to achieve the appropriate level of care. Increasing the SSI rate is not going to basically change the lot of the individual residing in the home. The little money given to the operator by way of an SSI increase is not going to make him a professional care giver.

Senator HEINZ. Let me rephrase the question. That's an important contribution. Suppose the director of the Office of Management and Budget, Dick Diamond, who is testifying now on the second floor which is where I disappeared to, said: I've been listening to your testimony over my Sony and you have got to do something. Here is $200 million. Do something. What should we do with that $200 million?

Mr. LAZARUS. Let me talk about the specific home.

Senator HEINZ. A billion dollars would increase the SSI level for all those people in board and care homes by roughly $100 a month.

Mr. LAZARUS. I would do two things.

First, I would increase the SSI rate to support the homes inflationary cost increases and I would also insist upon the State's making a contribution. In New Jersey, we contribute $1 a day. I would use most of the funds for rehabilitation programming, and I would not rely on the operator to purchase that service. I would much more prefer to rely on a non-profit in the community in the business of providing services and rehabilitation to do the programming in the home. I hope that answers the question.

Senator HEINZ. Thank you.

Are there any other comments?

The CHAIRMAN. Thank you, Senator Heinz.

Congressman Pepper, any following questions? If not, we want to thank this panel today. We have learned a lot from you and I hope that we will take your experiences and suggestions in good faith and try to constructively proceed to deal with this matter.

I will now call our third panel.

Thank you once again.

This panel will consist of Ms. Melva Colegrove, an investigative consultant with the Ohio Department of Health, from Columbus, Ohio; Ms. Pam Hinckley, owner and operator of a board and care home in Cleveland, Ohio; Ms. Mary Beth Africa, Long-Term Care Ombudsman, Altoona, Pennsylvania; Ms. Patricia Murphy, Long-Term Care Ombudsman, New York City; and Mr. Michael Coonan, Long-Care Ombudsman, Sacramento, California.

Senator HEINZ. Mr. Chairman, if you would yield while the witnesses are coming forward, I would like to have the privilege of saying a few words on behalf of my constituent, Mary Beth Africa, who is employed as an ombudsman in Blair County by the Triple A Agency there. She has been extremely helpful to the committee, both the majority and the minority, and I just want to commend her for the excellent work she has done. I hope we will have a chance to hear how successful she has been in taking providers who did not do a very good job and working with them to get them together to get a sense among the provider community of a very diverse and small, almost cottage industry. Indeed, this is a function that can be performed with professional excellence and a great deal of pride. I just want to point out that that is not only a worthy goal for providers but a very achievable one under the right circumstances, as will be demonstrated by Mary Beth's experience and the work she has done in Blair County.

The CHAIRMAN. Thank you, Senator Heinz.

That's a very good recommendation.

Before this panel begins, it is my understanding that Mrs. Colegrove has a video tape presentation. Is this correct?

STATEMENT OF MELVA COLEGROVE, INVESTIGATOR/ CONSULTANT, OHIO DEPARTMENT OF HEALTH, COLUMBUS, OH

Ms. COLEGROVE. We will ask that the lights be dimmed at this time and the video will be in progress.

[Transcript of video tape follows:]

[Videotape shows outside of board and care home.]

[Inspector at the bedside of a resident.]

INSPECTOR. Let's take a look at the lady with the fat feet.

She's got fat feet and a four-plus pitting edema. When you press in with your fingers the marks remain long after you have pressed in. That's not good at all. There is some edema here on her leg. It goes clear up to and including her knees. They are very edematous.

[Inspector goes to another bed-ridden resident.]

INSPECTOR. Let me look at your bedsores. This has been scraped with sheets. This is a sheet burn. More significant is the bedsore—it's hard—granulated in and abscessed out. She's got open tracks—I see three, and here's another small one. On her feet is peripheral cyanosis. You can see they don't bleach out good. You can see how

the color is distorted on this. They're not using their feet—nothing. Here's a healing bedsore.

[Inspector surveys contents of the refrigerator.]

INSPECTOR. This is wild game burger. This is not for sale. You can only use commercial foods to serve the elderly or any dependent person. This is food surplus materials.

We need to have our sanitarian come out and see this. We have got 11 packages or more of food that is dated 1984. It's freezer burned to death. Here are more packages of food dated 1984. It's no good. It should be destroyed right away. It's very dangerous.

We sure do have a lot of Kool Aid. Here's dog food. Everybody's got to have dog food. We sure have a lot of this.

[Inspector looking at a package of rice.] This is the type of food that you get from welfare. People who are on welfare get this extra commodity of food. Why it's here, I don't know because these people are paying her for their food. There are six packages of rice.

[Videotape changes scene to another location and scans from one resident's bed to another.]

MODERATOR. The following pictures were taken at an Ohio board and care home.

You see here a malnourished elderly woman who has not been moved in months and has developed severe contractions of her arms and legs.

This woman cannot open her eyes because they have not been cleaned.

This woman's leg has reached an advanced and dangerous stage of edema. The edema and bedsores have advanced to such a state that the skin is rotting off.

The bedsores on this man are so advanced that skin and muscle are exposed.

[End of videotape.]

The CHAIRMAN. Thank you very much. I believe Ms. Colegrove is our first witness. We are responsible and grateful to you for this video film

Before you make a statement, I'm perplexed. I need to ask a question. Why aren't some of the people we see in this home qualified to be in a licensed nursing home under the Medicare supervision?

Ms. COLEGROVE. They were qualified. They were removed from this home by an adult protective order to the county human service.

The CHAIRMAN. Through what order, please?

Ms. COLEGROVE. Adult protective order. This is the way our mechanism works. I evaluate the resident, I write the adult protective order when life and/or limb is endangered then the adult protective services of that county work with the families for a different placement site.

We immediately removed six people out of that home as their life and limbs were endangered.

The CHAIRMAN. Generally, when they go to a board and care home they are not qualified for a Medicare-approved nursing home. Is this correct?

Ms. COLEGROVE. No, it isn't.

From my experience people go to board and care homes for different reasons. They are elderly population who advance in age and physical deterioration and mental capacity; consequently, they are not the same as the resident that came into the home. They will then need a higher level of care.

The CHAIRMAN. It seems like these people are getting the lowest level of care.

Ms. COLEGROVE. Those people were retained at the home after they should have gone to a licensed skilled facility.

The CHAIRMAN. They were retained?

Ms. COLEGROVE. Retained in the board and care home after they should have gone to the licensed skilled facility. They were too advanced for the uneducated untrained operator to handle.

The CHAIRMAN. I don't want to misspeak, Congressman Pepper, but just while we were watching this, if I might try to quote you correctly, he said: ". . . you know, what we are watching is not in some third world poverty stricken country. This is in the United States of America. It is absolutely unbelievable. I hope I've quoted you properly * * *".

Mr. PEPPER. Correct.

The CHAIRMAN. Ms. Colegrove, go ahead with your statement. Because we are running late, we're going to try to hold our witnesses to three minutes. Thank you.

Ms. COLEGROVE. Mr. Chairman, and distinguished committee members.

I am Melva Colegrove, a registered professional nurse practicing in the State of Ohio.

I know of many board and care homes that provide excellent services and care to the elderly. I have been in such homes, consulted with the operators to assist them in maintaining such quality. In the course of my job duties with the Ohio Department of Health over the last four and one-half years, I have performed on-site inspections of over 300 such homes. In these homes I have found the following problems.

Adequate fluid and nutrition are not always provided.

Health care needs of the residents are not being included, including but not limited to, personal hygiene, personal care and nursing service.

In one unlicensed facility I observed a man with facial lesions—open, red and raw with drainage. He had not seen a physician. I observed an alert and oriented woman in another facility who was in bed. She had been incontinent and unable to control her elimination process. She laid in feces and urine from head to toe. She had an apical pulse of 30. She was immediately removed by adult protective services and sent to a licensed nursing home. The licensed nursing home took four days to stabilize her and to get her clean.

Another problem I see is improper use of restraining devices including chemical restraints and isolation.

I have seen elderly tied into chairs with old panty hose so they will not wander around. When such a device is used, it irritates the skin and you then have another of red and raw area. In one facility I observed a resident whose body was restrained to the chair, her arms restrained to the chair arms and her neck was restrained to the back of the chair. This woman could not turn her head—if she did she would actually have choked herself.

Another problem in board and care homes is that drug regimen reviews are not being performed and some of the residents are experiencing drug adversity and interactions.

Out-dated and non-prescribed drugs are being given.

Disruption of the integrity of the skin is another common problem in these homes, bedsores, static ulcers, red and raw areas, and scabies are common. I have observed elderly with multiple bedsores which had not been under the care of physicians. In one instance I counted a resident with 32 bedsores on a small, frail, elderly woman. The sores were infected and draining. In another home, I personally measured a bedsore and it was 14 inches in length—inches not centimeters.

Improper handling of the elderly resulting in bruises, moon-shaped nail marks and abrasions is a common problem, along with unsafe and often hazardous physical environment.

The control and containment of feces is a problem in board and care homes. For an example, I have observed fecal matters smeared on the walls and door of a board and care home which was operating as an unlicensed nursing home. Six months later at the court-ordered follow-up, the same fecal smears were still there on the wall. I stood in this operator's kitchen counting cockroaches scrambling over food articles and up and down the walls and I had to listen to the unlicensed operator criticize me for putting this information in my report.

At another facility I observed a five-gallon pail full of human excreta. Upon directly questioning of the operator, she stated that the commode was "emptied this morning."

Mr. Chairman, I will answer any questions that I can for you.

[The prepared statement of Ms. Colegrove follows:]

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RICHARD F. CELESTE
Governor

TESTIMONY TO

Senate Special Committee on Aging
United States Senator David Prior, Chairman
Ranking Member United States Senator John Heinz

House Select Committee on Aging

Subcommittee on Health and Long Term Care
United States Representative Claude Pepper, Chairman

Subcommittee on Housing and Consumer Interest
United States Representative James Florio, Chairman

Presented By

Melva J.S. Colegrove, RN, BA, MS
Investigator/Consultant
Ohio Department of Health

March 9, 1989

Mr. Chairman and distinguished committee members, I am Melva Colegrove, a registered nurse who is licensed to practice professional nursing in the state of Ohio. I know of many board and care homes that provide excellent services and care to the elderly. I have been in such homes, consulted with operators to assist them in maintaining such quality. However, due to the lack of standards and regulations such assistance is possible only when a facility operator asks for help. In the course of my job duties for the Ohio Department of Health over the past 4.5 years, I have performed onsite inspections of 306 unlicensed facilities which have been reported to be operating as nursing homes or rest homes rather than board and care homes.

The Ohio Department of Health cannot address the most common problems found in Adult Board and Care Homes because the department does not have the authority to regulate these homes. The department does have occasion to visit some of these when an allegation has been made that a home is operating as a nursing or rest home without the appropriate license. In these homes, the most common problems are:

1. Adequate fluid and nutrition is not provided,

2. Health care needs of residents are not being met, including but not limited to, personal hygiene, nursing and personal care,

3. Improper use of restraining devices, including chemical restraining and isolation,

4. Drug regimen review not performed resulting in some of the residents experiencing drug adversities land interactions,

5. Out-dated and non-prescribed drugs being given,

6. A high incidence in disruption of the integrity of the skin, e.g., bedsores, static ulcers, red/raw areas,

7. Improper handling of the elderly person resulting in bruises, moon shaped nail marks and abrasions,

8. Unsafe and often hazardous physical environment.

During such onsite inspections, I have witnessed and observed numerous catastrophic health care situations throughout all areas of the state. These problems are classified as:

I. ELDERLY NEGLECT: Services that would promote basic health and safety for the elderly are inconsistently practiced in unlicensed/unmonitored homes, consequently many elderly are living out their "golden years" in substandard situations and are just being "warehoused." Such neglect is demonstrated by:

A. Medical Neglect: The lack of health services is not an uncommon occurrence in unlicensed homes. In one home, I observed an elderly man who had a massive facial lesion which had foul smelling drainage and was open and raw. I observed an alert/oriented woman who was so weak she could not get out of bed and get to her bedside commode. She lay covered from head to foot in her own excreta. Her apical pulse rate was 30 beats per minute. She was transferred to a licensed skilled home, was diagnosed as having anterior heart block, grade II and required four days of care to get cleaned up and be stabilized.

Lack of medical care was observed with a resident who was emaciated, was purple up to his knees, was purple inside his mouth and in his nailbeds. This alert and oriented man stated to me, "..get me out of here or I will die.." He had not seen a doctor in over six months.

I have seen residents who have fallen, not received any medical attention and whose limbs are clearly out of alignment. Again I also observed a resident who was made to remove her arm splint to wash. The resident's fracture has healed but not in alignment therefore not functional.

In one facility I observed six residents who were paralyzed in one arm from strokes. All of these resident's hands were contracted in a fist formation. The area collected debris and residue, the skin areas of the hand touched, consequently with the unclean skin areas continuously touching, the area became infected. When the fingers were moved and slightly extended, chunks of skin and debris fell from the area.

Another resident I observed was unable to control her urine, was confused, on numerous antipsychotic medications and was not cognizant that her feet were infected from constantly being wet. Skin actually hung from her foot when her shoes were removed. Another resident of the same facility had cyanosis of the fingers, oral cavity, tongue and feet. Her feet were also exceedingly swollen from fluid. Upon listening to her lung fields, I found they were highly congested.

B. Restraining: I have seen elderly tied into chairs with old panty-hose so they would not wander about the facility.

When such a device is used the skin and tissues easily becomes red and raw. In one facility, I observed a resident who was body restrained by being tied into the geri-chair, her arms tied to the chair arms and her neck tied to the back. She could not turn her head because of the tight neck restraint.

C. Elimination: I have observed alert and oriented elderly being made to wear diapers to control their occasional dribbling instead of mini-incontinence pads being used or a planned bowel and bladder regimen instituted.

Control of incontinence is also done by indwelling catheters. All the numerous catheters I have observed in the unlicensed homes demonstrate purulent mucous plugs, tubing incrustation, all of which are signs of infection of the lower urinary tract.

D. Inappropriate as well as scarcity of attire are commonly seen in unlicensed facilities. Frequently the lack of underclothes, socks, shoes or arm covering during winter weather is seen. On one cool April day (temperature was 52 degrees Fahrenheit), I found residents in a facility attired only in cotton hospital gowns, restrained on bedside commodes in front of partially opened windows. The residents were restrained with pad-locked restraints to the chair frames. One resident had a contracted left leg which was unsupported and hanging in mid-air. Her right leg hung unsupported 6-8" from the floor.

E. Lack of Personal Hygiene: Impacted residue that looks like and smells like human excreta is frequently observed under the fingernails of the residents. Frequently these residents eat by using their fingers/hands rather than utensils. Another example of nail care being ignored is where residents have curled ram horn type of toe nail from shoe pressure when nails are not being cut. Accumulations of residue and debris are commonly seen between the toes, at hairline, in umbilicus, eyelashes and in the ears.

II. DISRUPTION OF SKIN INTEGRITY: I have observed elderly with multiple bedsores which had not been under the care of a physician. In one instance, I counted 32 bedsores on one small frail woman. These sores were infected and draining purulent material. In another instance, I observed a bedsore that measured 14 inches. This sore was down through all the muscles to the bone.

Many facilities have at least one resident who has some form of disruption of the skin. Since the skin is the body's first line of defense against pathogen entry and many elderly do not demonstrate overt signs that an infection is occurring, skin disruptions are of particular concern in the unlicensed homes where no nursing care is available. Rashes and red/raw perineal areas from sitting in wet diapers are commonplace in these homes. I have seen residents who have multiple lesions from scabies, leg ulcers and multiple bruising.

In summary, elderly who demonstrate altered skin conditions need ongoing health evaluation. Caregivers must be made to understand that retaining such residents is a form of exploitation and cannot be tolerated.

III. FOOD/FLUID DEFICIT: I have observed elderly who have demonstrated physical signs of food/fluid deficits. At one facility, two alert/oriented bedfast residents demonstrated such signs and asked me to give them water. I personally gave each resident approximately 500 cc of water to drink.

I have personal knowledge that at one facility, 10 residents were served tuna fish sandwiches and cabbage for their lunch. The operator openly admitted that a 3-4 ounce can of tuna was all that was used to feed 10 residents. There was approximately one cup of cabbage used. During the inspection, the operator sent her helper out to buy some cookies. When the cookies were offered to the residents, they literally grabbed as many cookies as their hands could hold along with shoving whole cookies into their mouths. During the inspection of this home, four residents demonstrated overt signs of malnourishment and were subsequently hospitalized land transfused with whole blood.

In another facility, I observed an untrained person feeding a bedfast resident by squirting liquids with a syringe and plunger down her throat while the resident lay on her back. Such a practice is exceedingly hazardous because of the possibility of choking and aspirational pneumonia which can occur. Additionally, I have seen elderly literally grabbing food from other residents plates during mealtimes. Alert residents will openly state that they are hungry.

I have been witness to the fact that in the vast majority of Board and Care homes, fluids are not readily available to the elderly. The main reasons given for the lack of providing fluids is that the elderly's feet are swollen.

IV. MEDICATIONS: The use of physician-prescribed and over-the-counter drugs are problems in unlicensed/unmonitored

homes. Some of the problems I have encountered throughout the state range from inappropriate storage of drugs, i.e., drugs not segregated per individual resident and unlabeled drugs placed in bottle caps, unlabeled as to the drug and the resident. Some residents were disoriented and confused. Medications are not always administered as prescribed by the physician or per basic standards to enhance drug effectiveness and to reduce side effects. I have seen drugs administered to sick adults through such degrading tactics as using a baby bottle. I have seen drugs on hand which were outdated, drugs including narcotics kept after a resident has left the facility. Such drugs should be destroyed immediately.

In one facility, a public health nurse who accompanied me spent two hours recording the names, doses of drugs which had been retained from previous residents. At this facility, the operator (who is neither a doctor nor a pharmacist) admitted to prescribing these drugs and dispensing them to other residents. I have had caregivers admit to administering drugs for fees even though the resident was alert and oriented and able to be in charge of his own medication. I have heard a physician testify in court that he had not examined a residents particular home for eight years but continued to renew the prescription and prescribed drugs as requested by the operator.

Many unlicensed facilities do not maintain any type of records. As a result, there are duplications of drugs by trade and generic names prescribed and administered even though they are chemically the same and drug regimen reviews are not done. In addition, I have observed multiple antipsychotic drugs administered to keep residents sedated and so that the caregiver will not be bothered. Many of such residents do not even have a primary or secondary diagnosis of mental illness.

V. PHYSICAL ENVIRONMENT: The internal, as well as external physical environment can contribute to an unsafe living situation. The control and containment of human excreta is an ongoing problem. I've observed fecal matter smeared on the walls and doors at the time of initial inspection. Six months later, at the court-ordered follow-up visit, the same dried fecal smear remained. As I stood in the operator's kitchen counting cockroaches scrambling over food articles and walls, I had to listen to the unlicensed operator criticize me for placing such information in the initial report.

I have been witness to residents being made to use rudimentary makeshift equipment. In one instance, the facility's bathroom was within 25-30 feet of an open makeshift commode.

Additionally, I have observed unsafe physical environment such as, smoke detectors being made non-functional by battery removal, lack of sufficient beds for the number of residents, beds so closely placed that egress is almost impossible, residents living in unheated barns, garages, cellars and attics. These situations are, at best, unsafe and degrading; however of greater concern, egress is often blocked, locked or obstructed. This creates a serious situation in case of fire, flood or other natural disasters. Uncontrolled animals in the house also cause a problem. I have been witness to a facility cat being let in from the outside, then jumping up on the table and eating the resident's food.

At one facility, I observed diapers that were soiled with human excreta tossed onto the facility's store of potatoes.

Currently, the state of Ohio can enjoin operators of Board and Care homes that are in reality illegal nursing homes by going through the court system. Sometimes operators move outside the state's jurisdiction by crossing the state line and reopening in Kentucky, Michigan, West Virginia, and Pennsylvania.

In other instances, operators who have been enjoyed by the courts avoid penalty by removing those residents who require little care and consequently pay less per month and keeping two residents who are most in need of skilled care and whose families pay a higher fee. Since Ohio law allows an operator to provide skilled nursing care as long as there are fewer than three unrelated residents involved, the operator is within the law.

At present, the Ohio Department of Health has no guaranteed access to unlicensed homes. In an attempt to resolve a complaint, and gain entry, a criminal search warrant must be obtained. Even with search warrants and a law officer as an escort, the regulatory staff cannot be assured of entry. I personally have been physically assaulted when a search warrant was served and had dogs sicked on me by unlicensed operators.

Mr. Chairman and members of the committee, I wish to thank you for your time and attention, and I will be glad to answer any questions to the best of my ability.

The CHAIRMAN. Thank you very much, Mrs. Colegrove, for your statement and once again for bringing the video.

Ms. Pam Hinckley, owner and operator of a board and care home in Cleveland, Ohio.

STATEMENT OF PAM HINCKLEY, OWNER/OPERATOR, BOARD AND CARE HOME, CLEVELAND, OH

Ms. HINCKLEY. Hello. I do feel targeted in a way because I'm listening here and everything is going on bad in these homes and I feel—oh, no.

The CHAIRMAN. Well, let's hear the other side.

Ms. HINCKLEY. I do run an adult family home in Cleveland, Ohio, with my husband. I have been working with the elderly in group homes and private homes over the past 11 years. We are approved by the county department of human services and I do attend the care providers support group meetings.

We can accommodate up to five residents as far as our zoning is concerned. We did have problems with this at one time. Each resident is provided with a furnished room—private or shared—three well-balanced meals and snacks, laundry, with supervised medications, and we help with the guidance for daily living activities. We also do provide in-home foot care by a regular podiatrist on a regular basis and we can provide access to medical services and local senior citizen activity center.

We have a nurse that we have been working with now for the past year who comes in every six to eight weeks. She goes over the general health of all of our residents. If she sees any problems or if the residents have any questions, she's really good as far as providing information on such things as diets, medications, or even for that matter physical or social changes in the home.

All of my residents are over 65. Most were placed there by their relatives and they were placed just because they needed to be with somebody because they weren't eating right or they weren't taking their medication on time. Most of my residents are pretty well up and about. I have nobody in bed. I have nobody that needs any skilled nursing care.

We also offer the resident a sense of belonging and I pride myself on our family oriented atmosphere. I have two kids myself. I have a three-year-old boy and an eight-year-old girl. We have a dog and birds. We live in a old fashioned type farm house. It is kept up-to-date. It isn't as horrifying as some of the stories I've heard here about homes. We try hard. We have a good interaction with our residents and a good rapport with the residents and their families.

Most of my residents have been with me for at least a year or more. Some of them were even with me at the time when I had my three-year-old. They do stay with us, I would say, until death do us part. When we do see signs of weight loss or gain, or incontinence, or if they would be in need of skilled nursing care—I do not diagnose this either, so don't take my word on this—we do work closely with the family doctors. Anyway, when we do see them going down hill, we do attend to their needs. We do make sure that they are watched by a physician or the nurse. When the time comes to say good bye, we do let them go. Only once have I had to have a resi-

dent placed in a nursing home. Most of the people have stayed with me until death.

As it stands in Ohio today, we do have a house bill that is currently pending before the House of Representatives. I think it is great. I wish it would pass now. We've been waiting for years for some type of regulations or standards to help us get our homes organized. We know that we're not perfect at what we're doing. I know that I'm not perfect. I do try as far as diets and medications to keep up with things as much as I can. I don't want to harm my residents in any way. I want them to enjoy living with me and I want them to stay with me until death. I enjoy doing this for a living.

I know that you are fully aware that there is a lot of abuse in these homes and I am fully aware of it too. I have worked for a few of these homes that you could say are abusing or neglecting the elderly. That is one of the reasons why I started my own. I could give you all kinds of examples of abuse in these homes and I just don't think it's necessary now. You have heard and seen quite a bit already.

One thing I would like to say is that it is very easy for care providers to go into hiding at these homes. It is very easy. We can place ads in papers. We can go to social service departments. We can contact the friends or relatives of the people that we have taken care of to get access to residents to move into our homes. It's quite easy to fill up a home.

It was brought up earlier about Social Security checks. It's easy to cash a Social Security check. Have a resident sign it, take your resident to the bank, and they will turn all the funds over to you. It is that simple. I won't handle finances at all for any of my residents. I just refuse. I have all of the residents in their home—their families pay me directly. They write a check direct to me. I do deposit and I even pay tax on it. We keep up pretty well with records and it works out well.

Most of the abuse and neglect that you have heard about in these homes are taking place in homes that I would say are in hiding. These are the homes that aren't approved or licensed or regulated by any type of agency. They don't have any type of help or organization coming in to check on these residents. These are the homes that you have to go after. It's the ones that are trying to tell you what we do for a living and are trying to get help—why would I be here today if I was abusing my residents. I wouldn't subject myself to you. Most care providers that operate these kinds of homes, you would know right off the bat. You could talk to a few of them and just by talking to them and by looking at their own personal appearances, you could tell just by their attitudes whether they should take care of residents or not. It's that easy to differentiate the different types of care providers.

[The prepared statement of Ms. Hinckley follows:]

TESTIMONY

BEFORE THE U.S. SENATE SPECIAL COMMITTEE ON AGING

for a hearing on

BOARD AND CARE: A FAILURE IN PUBLIC POLICY

MARCH 9, 1989

PAM HINCKLEY
OWNER/OPERATOR, BOARD & CARE HOME
CLEVELAND, OHIO

To Chairman, Sen. David Pryor, Sen. John Heinz and Members of the Committee,

I am Pam Hinckley and with the help of my husband, operate an adult family home in Cleveland, Ohio. Both of us have worked for several group homes and private homes as well, over the past eleven years and opened our own home almost five years ago. Our home is approved by the Cuyahoga County Department of Human Services and I am also quite active in local careprovider support groups.

Our home can accommodate up to five residents and all of their living quarters are located on the first floor of the home. Each resident is provided with a furnished room (private or shared), three well-balanced meals and snacks,laundry, supervision of medications, and guidance for daily living activities. We can also provide in-home foot care on a regular basis, accessto medical services and the local senior citizen activity center and transportation to and from both.

We also have a registered nurse, who participates in Programs for Older Adults sponsored by Lutheran Medical Center, that visits our home every six to eight weeks. The nurse checks the resident's vital signs, vision, hearing, and general health. If either I or the resident has any questions pertaining to diet, medication, physical/emotional changes, etc., she answers our questions to the best of her ability, most of the time we are provided with written information. Lutheran Medical Center also offers transportation to and from medical appointments when needed.

All of our residents are over 65 years old. Most were placed by relatives who felt their relative was not quite ready for any type of confined institutional-type living arrangement. The families accepted the fact that supervision was needed for their relative but also wanted them to continue to have a normal home life.

Our home offers the resident a sense of belonging and a family-oriented atmosphere besides the basic necessities. We have two children, a dog, and birds. Life is far from oeing dull and dreary with them living in the home. The residents love to listen to my daughter reading aloud and some of them actually play cars and trucks with my three year old son. The dog is constantly showered with love, affection, and food.

Many of the residents keep busy by sharing some of the household chores and all take pride in keeping their rooms neat and clean. A few of the residents participate in activities at the senior center and all join in for a Catholic service, no matter what their denomination, every Monday morning.

Holidays, birthdays, and even the start of a new season are our social events during the year. Most of the residents love to decorate the home and participate in each holiday project. Some of the projects include decorating the tree for Christmas, dying Easter eggs, enjoying fireworks on the Fourth, some even go trick-or-treating on Halloween. Birthday parties are a luxury for most of them when their special day rolls around. During the spring, summer, and fall, the residents love to take walks and even help with some of the gardening. Picnics and other outdoor activities are also favorites at these times of the year.

As time goes by, each resident has his own special place in our family. We learn how each one feels and responds to any given situation. My immediate family seems to fill a void for most of them who otherwise, felt their lives were finished. Some of the residents felt they would 'lose' their independence but quickly realize that they may voice their own opinions, come and go as they choose, and continue to handle their own affairs to the best of their abilities. We try to show them to be proud of who and what they are and to help them to keep their independence as much as possible. There have been times when a resident needed more care than we could offer them. A resident can show symptoms of incontinence,

confusion, weight loss or gain, sleep disorders, trouble with walking, etc. Should any of these symptoms appear, I immediately contact the nurse and/or their doctor. The resident is then seen by the nurse or doctor and if the need arises, is then hospitalized. The problem is either corrected and the resident returns home or I am notified that the resident is in need of skilled nursing care and needs to be placed into a nursing home. The majority of our past residents lived with us until they passed away.

I hope I have given you an accurate picture of our home. It is difficult to describe when the home and the job itself entails so much. Not every adult care home operates in this manner nor is it set up the same way. Every adult care home has its own unique qualities and no two homes are alike. Iam proud of the atmosphere we have established and want to continue to operate in some-what the same fashion, although I will certainly welcome changes for the good of my family and home.

Right now there is a bill that has been presented before the Ohio House of Representatives (H.B. 253). This bill could give careproviders, like myself, a chance to be truly recognized by all of you, many organizations, and the people of the state of Ohio, that our homes can and do provide a very important alternative living arrangement for many of our elderly citizens. Many careproviders agree how urgent the need is to have all of adult care homes monitored on a continual basis by one department, so that all of us can be guided by these specific regulations and ensure the careproviders, the residents and the home itself, protection.

As it stands today in Ohio, we do not have specific guidelines for our homes. Although, many adult care homes try to set some type of standards for their home. Without regulations, just about anyone can operate an adult care home with good quality care or not. This is the biggest reason why so much of the abuse and neglect continues in adult care homes. With the help of regulations enforced most of the abuse and neglect in these homes would or could not continue. Many of the abusive careproviders would be forced to come out of 'hiding'.

There are many adult home care operators 'in hiding', in Ohio. These homes are not approved or licensed by any agency,and are operated by clever careproviders. These providers are fully aware of the demand for homes and are also aware of the fact that Social Security checks do not need to be deposited to receive the cash, The provider has the resident sign and cash these checks for them so that noone is aware who really receives the cash. It is relatively simple to get prospective residents. You can either place an ad in the local newspapers and/or contact the social service departments in nearby hospitals. Most social workers just do not have the time to check on each home and most are pressured to find a home for these unfortunate people. Many of the residents have little income and no family, so they jump at the chance to live with someone who supposedly cares. Once they are placed with these careproviders it is very difficult for them to reach out for help. They are more or less caught in a trap. Thay have little or no money left and do not have access to contact someone, anyone.

Most of the abuse and neglect are taking place in homes like the one I just described. These careproviders are very seldom home, refuse to pay some or all of utilities, buy little food, and offers little or no assistance for personal or grooming needs. Most of their residents are subjected to horrible physical and/or verbal abuse and receive little or no medical attention.

Then there are those careproviders who have beautiful adult care homes but are under so much stress because of the job itself or their own personal problems. These providers offer a clean home and excellent food but are lacking in patience and tender loving care because of their own attitudes or personal problems. Some of these providers should not be allowed to take in residents, while others could offer quality care with just a little bit of assistance. It is very difficult to find people who are willing to work with the elderly and I do speak from experience. Good 'help' is hard to find. If only we had a decent respid care service that could offer careproviders a temporary break from their jobs, at a reasonable cost (many providers are taking in residents with low incomes) to help relieve the provider from some of the stress and pressures of operating an adult care home. It took me several years to find someone decent and trustworthy to come into my home and again I am lucky to have finally found such a person.

Finally, there are homes in which the careprovider takes in residents (again, usually at a low income) that try hard to offer a safe and healthy home and quality care but have very little income or resources from which to work with. These careproviders are usually in their fifties or older, have a small income for themselves, and most have had little or no education. They are for the most part loving and caring people and are trying to help others and themselves to survive. Their residents are fed well and given quality care but may skim on such items like toiletries, cleaning products, laundry supplies, household furniture and supplies, etc. These careproviders might not live up to the same standards as yours or mine but most are more than willing if given the opportunity. This may still seem like abuse and neglect to you and I am not condoning this type of living arrangement but with just a few adjustments of their budget or maybe they could qualify for some type of government assistance and turn their home around. This type of careprovider is usually not aware of the different organizations or services that possibly could help them.

Our home is very lucky to have at least a few organizations willing to work with us. One organization that I have previously mentioned is the Program fo Older Adults, which is affiliated with Lutheran Medical Center. Another is the local OMBUDSMAN program which aids in placements and referrals to approved and licensed adult care homes. They also help coordinate possible nursing home placements and last but not least, Services to Adult Care Homes, a project of the Lutheran Metropolitan Ministries, directed by Ms. Sally Reisacher.

Without the help of Ms. Reisacher, our home would have been closed a couple of years ago. We were having serious problems with the city of Cleveland over zoning issues. Ms. Reisacher referred us to an excellent attorney (at a minimal cost) and with both of their services, the cooperation of our neighbors and residents all of our problems were solved. This is only one example of what Ms. Reisacher's program offers. She has time and again dealt with many problems in our home alone, ranging from information on salmonella to helping a resident receive medical attention to finding a nearby senior citizen activity center. Again, these are only a few examples. In all honesty, we could not operate our home at a quality level, without the help of Ms. Reisacher and her program. It is unfortunate that all careproviders do not have access to services and programs such as I have described.

I know that this testimony must seem quite lenghty to a few of you but I I am only trying to impress upon you as many details and suggestions as I can. We desperately and urgently need your help. If we do not get help soon, 'good' adult care homes will continue to struggle to prove the quality services which they offer while the 'bad' homes will continue to offer more abuse and neglect. We all want and need to assure our elderly citizens nothing less than a safe and healthy alternative living arrangement for those in need of one.

Iwould also like to thank all of you for your time, patience, and understanding.

Pam Hinckley
4832 Rocky River Drive
Cleveland, Ohio 44135
(216) 267-9549

The CHAIRMAN. I will have some questions and possibly Senator Heinz will in a moment. If we could get the other witnesses to come forward, we will come back to the questions.

Ms. HINCKLEY. Thank you.

The CHAIRMAN. You made a very fine statement.

Mary Beth Africa.

STATEMENT OF MARY BETH AFRICA, LONG-TERM CARE OMBUDSMAN, ALTOONA, PA

Ms. AFRICA. I hope the old saying goes that you do save the best for last.

Pennsylvania is chiming in here this morning to say personal care is alive and well. In Blair County we have experienced what I consider to be a renaissance in the board and care industry.

I am an ombudsman in Pennsylvania. Prior to this I had several years experience in long-term care administration in the State of Alabama. And earlier, years of experience in the State of Kentucky. So I speak not only from my experience within the Commonwealth of Pennsylvania but also as I see problems which have existed in Alabama and Kentucky. As we have heard today, these problems do transcend State lines.

I need not go into a lot of detail regarding the abuse, neglect and exploitation which have taken place. You have already seen and heard pretty much of what I might speak to you about.

In Blair County, Pennsylvania, we have 28 licensed personal care homes ranging from 4 to 179 beds which care for individuals. I might say that we do have problems. I think in any business there are problems. Personal care? Yes. With the ombudsman program in Pennsylvania, there has just been passed legislation that not only goes with the Older Americans Act Federal program but has instituted a State generic ombudsman program providing the ombudsman with more teeth to dig into the situations and problems and assist the providers in progress.

Secondly, I am holding in my hand what has existed currently in the Commonwealth of Pennsylvania as its regulations. It is not very voluminous I might add and is somewhat sketchy in content. For instance: a provider must be of good character and personal integrity with good physical and mental health. Yet there are providers within the Commonwealth with criminal records, known mental health histories and communicable diseases which could be passed on to many residents. I am concerned about this.

In November, Pennsylvania legislators passed what is now Act 185, which is what I consider personal care reform. It addresses many of the issues, problems and concerns that have been expressed with all three panels today. May I add that we are working within the Commonwealth of Pennsylvania to assist the providers with a very aggressive free training program, not only for the operators but for the staff, also. Trainers include attorneys, physicians, nurses, health care professionals, legal professionals, regulatory agency representatives and legislators. This knowledge will assist the home operators to deliver quality care. You asked some of the ombudsmen earlier what it would take to provide quality care. I believe the training which Blair County, Pennsylvania is providing. I

would encourage you to come and visit us and see what we are doing with training and how the providers have a real pride and sense of achievement in delivery of care.

Also, within Act 185 we have now the legal presence of non-mobile residents within the personal care home. These people may physically be non-mobile, such as a stroke patient, multiple sclerosis patient, or be what is considered mentally non-mobile with Alzheimer's disease. I have seen these residents restrained, lying in urine and feces. I know of cases where residents have been physically forced to take medication, which resulted in personal injury and hospitalization. There are instances when it has taken over 30 minutes with a planned fire drill to evacuate less than 20 people—two of those needed emergency hospitalization and care. I find this to be heinous. This is why we are encouraging and working in Pennsylvania and in Blair County to improve these issues.

Lastly, quality care is costly, as we have discussed. Pennsylvania does have a State personal care home supplement of $114.90. It is still inadequate. The providers who do want to provide quality care and are accepting the neediest of the needy, are not able to accomplish these goals as they would like with the amount of payment they are receiving. Notwithstanding, with the presence of these non-mobile people their needs are greater. Durable and expendable medical supplies and personal care items must be furnished often at the cost of the provider.

I am interested, concerned and very pleased that you are giving national attention to the board and care issues and, would encourage you to please come visit Blair County. Observe what we are doing and how our providers are excited about the care they are giving. Unfortunately, within Pennsylvania when a home needs to be closed it can take as long as two to two and one-half years in the appeals process for closure and relocation of the unfortunate residents.

I thank you for your attention to these efforts and if Pennsylvania and Blair County can assist and provide you with anything, we will be happy to do so.

[The prepared statement of Ms. Africa follows:]

TESTIMONY

BEFORE THE U.S. SENATE SPECIAL COMMITTEE ON AGING

for a hearing on

BOARD AND CARE: A FAILURE IN PUBLIC POLICY

MARCH 9, 1989

MARY BETH AFRICA
OMBUDSMAN/ADVOCATE
ALTOONA, PENNSYLVANIA

Senator Pryor, Senator Heinz, Congressman Pepper, Congressman Florio, members of the Committees and guests: my heart is full as I convey my concerns regarding the need for national reform within the board and care industry. I am currently a long-term care ombudsman in Pennsylvania. Prior to this, I was employed in long-term care administration in Alabama and, earlier, involved as a student volunteer in board and care homes in Kentucky and Pennsylvania; in all, experience over a 15 year span. Generally, home operators endeavor to provide adequate care to residents aged 18 to over 100 who are elderly, mentally ill, mentally retarded, physically handicapped, or a combination of these. Many are SSI recipients. The problems I have seen transcend state lines and can be partly categorized as follows:

1.) Training - Needless involuntary mental health commitments, hospitalizations, damages to property or persons, and even death occur because staff of board and care homes are not trained in areas such as first aid, emergency planning, mental illness, non-violent crisis intervention, fire safety and prevention. Pennsylvania recently passed Act 185 which mandates training in these and other crucial areas. Blair County, Pennsylvania went one step further by the creation of the Personal Care Provider's Advisory Committee. One of the functions of this Committee is to provide free training to board and care personnel in the aforementioned areas, as well as others.

2.) Mobility - Physically and mentally nonmobile persons are becoming more prevalent in board and care facilities. Problems such as advanced Alzheimer's Disease, Multiple Sclerosis and Stroke can render individuals "nonmobile." Nonmobility creates the need for additional staffing, durable and expendable medical supplies and, often, the need for architectural modifications to ensure freedom from access barriers. Frequently, those residents can only offer the same SSI payment as those residents whose care needs are less costly to the operator. Nonmobile indigent persons are the most needy in all respects, but the least attractive to prospective board and care homes. Certainly, they too must have assurance of quality care.

3.) Fiscal impact - Quality care is a costly issue. SSI payments are inadequate to meet expenses incurred by board and care operators. Pennsylvania is fortunate to have a separate monthly Personal Care Home Supplement available to SSI recipients and certain low income residents of licensed board and care homes. Still, this amount ($114.90) falls short of the mark. Compounding this problem, supplement recipients receive a mere $25 monthly as their Personal Needs Allowance. Out of this they must purchase over the counter medications, personal hygiene items, clothes and other incidentals.

The issues I have presented pertaining to national board and care reform are merely the tip of the proverbial iceberg. However, I am encouraged by the efforts being taken in Blair County, Pennsylvania to confront the needs of the board and care industry. I would invite members of the Committee to visit and experience firsthand our progress. Yes, national reform of the board and care industry IS necessary AND possible. Thank you for focusing major attention to this issue.

HOUSE AMENDED

PR 1460, 1920, 3110,
3602, 3904 **Printer's No.** 3949

THE GENERAL ASSEMBLY OF PENNSYLVANIA

ACT 185

HOUSE BILL

No. 1278 Session of 1987

INTRODUCED BY RICHARDSON, KUKOVICH, PISTELLA, DAWIDA, WIGGINS, HUGHES, GLADECK AND HUTCHINSON, APRIL 29, 1987

AMENDMENTS TO SENATE AMENDMENTS, HOUSE OF REPRESENTATIVES, NOVEMBER 30, 1988

AN ACT

Amending the act of June 13, 1967 (P.L.31, No.21), entitled "An act to consolidate, editorially revise, and codify the public welfare laws of the Commonwealth," further providing for the licensing and regulation of personal care homes and adding penalties; establishing the Intra-Governmental Council on Long-Term Care and providing for its powers and duties; and further providing for regulations by the department.

The General Assembly of the Commonwealth of Pennsylvania hereby enacts as follows:

Section 1. Section 211 of the act of June 13, 1967 (P.L.31, No.21), known as the Public Welfare Code, added July 10, 1980 (P.L.493, No.105), is amended to read:

Section 211. State Plan for Regulating and Licensing Personal Care [Boarding] Homes.--(a) In accordance with the statutory authority and responsibility vested in the department to regulate nonprofit [boarding] homes for adults which provide personal care and services and to license for profit personal care [boarding] homes for adults, pursuant to Articles IX and X,

the department shall develop and implement a State plan for regulating and licensing said facilities as defined by section 1001 of this act.

(b) In developing rules and regulations for the State plan, the department shall:

(1) Distinguish between personal care homes serving less than eight persons and personal care homes serving more than eight persons.

(2) By July 1, 1981 adopt rules relating to the conduct of owners and employes of personal care [boarding] homes relative to the endorsement or delivery of public or private welfare, pension or insurance checks by a resident of a personal care [boarding] home.

(3) Not regulate or require the registration of boarding homes which merely provide room, board and laundry services to persons who do not need personal care [boarding] home services.

(c) Within three months following the effective date of this act, the department shall submit to the General Assembly for comment and review, and publish in the Pennsylvania Bulletin in accordance with the provisions of the Commonwealth Documents Law relating to the publication of regulations, a preliminary State plan for regulating and licensing personal care [boarding] homes.

(d) The preliminary plan shall include, but is not limited to, the following:

(1) Coordination of the department's statutory responsibilities with those of other State and local agencies having statutory responsibilities relating to personal care [boarding] homes, with particular attention given to the Department of Labor and Industry, the Department of

Environmental Resources, the Department of Aging and the Pennsylvania Human Relations Commission. The Department of Labor and Industry shall promulgate rules and regulations applicable to personal care [boarding] homes on a Statewide basis consistent with size distinctions set forth in subsection (b) pertaining to construction and means of egress.

(2) Recommendations for changes in existing State law and proposed legislation to:

(i) Resolve inconsistencies that hinder the department's implementation of the State plan.

(ii) Promote the cost efficiency and effectiveness of visitations and inspections.

(iii) Delegate to other State and local agencies responsibility for visitations, inspections, referral, placement and protection of adults residing in personal care [boarding] homes.

(iv) Evaluate the State's fire and panic laws as applied to personal care [boarding] homes.

(3) Recommendations for implementation of fire safety and resident care standards relating to personal care [boarding] homes by cities of the first class, second class and second class A.

(4) A programmatic and fiscal impact statement regarding the effect of the plan on existing residential programs for the disabled, including but not limited to skilled nursing homes, intermediate care facilities, domiciliary care homes, adult foster care homes, community living arrangements for the mentally retarded and group homes for the mentally ill and the effect of the plan on recipients of Supplemental Security Income.

(5) Cost analysis of the entire plan and of all regulations that will be proposed pursuant to the plan.

(6) Number of personnel at the State, regional and county level required to inspect personal care [boarding] homes and monitor and enforce final rules and regulations adopted by the department.

(7) Process for relocating residents of personal care [boarding] homes whose health and safety are in imminent danger.

(e) If the department deems that it is in the best interest of the Commonwealth to develop a plan for implementation on a phased basis, the department shall submit a detailed schedule of the plan to the General Assembly which shall be part of the preliminary State plan.

(f) Within six months of the effective date of this act, the department shall adopt a final State plan which shall be submitted and published in the same manner as the preliminary plan.

(g) The final plan shall include the information required in the preliminary plan and, in addition, the cost to operators of personal care [boarding] homes for compliance with the regulations.

(h) At no time may the department change, alter, amend or modify the final State plan, except in emergency situations, without first publishing such change in the Pennsylvania bulletin in accordance with the Commonwealth Documents Law relating to publication of regulations and without first submitting the proposed change to the General Assembly for comment and review. In an emergency, the department may change, alter, amend or modify the State plan without publishing the change or submitting the change to the General Assembly; but,

within thirty days, the department shall submit and publish the change as otherwise required.

(i) The State plan shall not apply to any facility operated by a religious organization for the care of clergymen or other persons in a religious profession.

(j) Prior to January 1, 1985, department regulations shall not apply to personal care [boarding] homes in which services are integrated with, are under the same management as, and on the same grounds as a skilled nursing or intermediate care facility licensed for more than twenty-five beds and having an average daily occupancy of more than fifteen beds. Prior to January 1, 1985 the department may require registration of such facilities and may visit such facilities for the purpose of assisting residents and securing information regarding facilities of this nature.

(k) Any regulations by the department relating to the funding of residential care for the mentally ill or mentally retarded adults and any regulations of the Department of Aging relating to domiciliary care shall use as their base, regulations established in accordance with this section. Supplementary requirements otherwise authorized by law may be added.

(l) After initial approval, personal care [boarding] homes will be inspected annually need not be visited or inspected annually; provided that the department shall schedule inspections in accordance with a plan that provides for the coverage of at least seventy-five percent of the licensed personal care [boarding] homes every two years and all homes shall be inspected at least once every three years.

(m) Regulations specifically related to personal care homes

or personal care [boarding] home services adopted prior to the effective date of this act shall remain in effect until superseded by a final plan adopted in accordance with this section.

Section 2. The act is amended by adding sections to read:

Section 212. Intra-Governmental Council on Long-Term Care.--

(a) The General Assembly hereby establishes the Intra-Governmental Council on Long-Term Care.

(b) The Intra-Governmental Council on Long-Term Care shall be composed of and appointed in accordance with the following:

(1) The Secretary of Aging.

(2) The Secretary of Community Affairs.

(3) The Secretary of Health.

(4) The Secretary of Public Welfare.

(5) The Insurance Commissioner.

(6) Two members of the Senate, one appointed by the President pro tempore and one by the Minority Leader.

(7) Two members of the House of Representatives, one appointed by the Speaker of the House of Representatives and one by the Minority Leader.

(8) One representative from the Pennsylvania Council on Aging.

(9) One representative of the personal care home industry, who shall be an owner or administrator of a licensed personal care home, appointed by the Governor.

(10) Such other members of the public who represent special needs populations, provider communities, business, labor and consumers as the Governor shall appoint.

(c) The Secretary of Aging shall serve as chairperson.

(d) (1) The terms of the Secretary of Aging, the Secretary

of Community Affairs, the Secretary of Health, the Secretary of Public Welfare and the Insurance Commissioner shall be concurrent with their holding of public office.

(2) The terms of the members of the Senate and the House of Representatives shall be concurrent with the terms of the appointing officer.

(3) Nongovernmental members shall be recommended by the Secretary of Aging for appointment by the Governor and shall serve until their successors are appointed.

(e) The Intra-Governmental Council on Long-Term Care shall have the following powers and duties:

(1) To consult with the department and make recommendations on regulations, licensure and any other responsibilities of the department relating to personal care homes.

(2) To perform such other duties as the Governor may assign in planning for long-term care services.

(f) The department, in developing rules and regulations for licensure of personal care homes, shall take into consideration the recommendations of the Intra-Governmental Council on Long-Term Care.

Section 213. Personal Care Home Administrator.--(a) After December 31, 1990, all personal care homes shall identify and appoint a personal care home administrator or administrators who meet the qualifications provided in this section.

(b) A personal care home administrator shall:

(1) be at least twenty-one years of age and be of good moral character; and

(2) have knowledge, education and training in all of the following:

(i) fire prevention and emergency planning;

(iii) first aid, medications, medical terminology and personal hygiene;

(iiii) local, State and Federal laws and regulations;

(iv) nutrition, food handling and sanitation;

(v) recreation;

(vi) mental illness and gerontology;

(vii) community resources and social services;

(viii) staff supervision, budgeting, financial record keeping and training; or

(3) be a licensed nursing home administrator. The department may establish separate standards of knowledge and training for licensed nursing home administrators who wish to operate a personal care home. no regs established for this

(c) The department may promulgate regulations requiring orientation and training for all direct care staff in a personal care home. Admin. Ensure staff trained in above.

(d) By June 1, 1989, the department shall by regulation develop such standards for knowledge, education or training to meet the standards of this section.

(e) If not otherwise available, the department shall schedule, and offer at cost, training and educational programs for a person to meet the knowledge, educational and training requirements established by this act.

Section 3. Section 1001 of the act, amended July 10, 1980 (P.L.493, No.105), is amended to read:

Section 1001. Definitions.--As used in this article--

"Adult day care" means care given for part of the twenty-four hour day to adults requiring assistance to meet personal needs and who, because of physical or mental infirmity, cannot themselves meet these needs, but who do not require nursing

care.

"Adult day care center" means any premises operated for profit, in which adult day care is simultaneously provided for four or more adults who are not relatives of the operator.

"Boarding home for children" means any premises operated for profit in which care is provided for a period exceeding twenty-four hours for any child or children under sixteen years of age, who are not relatives of the operator and who are not accompanied by parent, individual standing in loco parentis or legal guardian. The term shall not be construed to include any such premises selected for care of such child or children by a parent, individual standing in loco parentis or legal guardian for a period of thirty days or less, nor any such premises conducted under social service auspices.

~~"Case management" means, in consultation with and upon the approval of the resident, to assist such resident in the development and implementation of an individualized plan for activities and services both within and outside the personal care home.~~ <--

"Child day care" means care in lieu of parental care given for part of the twenty-four hour day to children under sixteen years of age, away from their own homes, but does not include child day care furnished in places of worship during religious services.

"Child day care center" means any premises operated for profit in which child day care is provided simultaneously for seven or more children who are not relatives of the operator, except such centers operated under social service auspices.

"Direct care staff" means a person who directly assists residents with activities of daily living, provides services, or

is otherwise responsible for the health, safety and welfare of the residents.

"Facility" means an adult day care center, child day care center, family day care home, boarding home for children, mental health establishment, personal care home [for adults], nursing home, hospital or maternity home, as defined herein, and shall not include those operated by the State or Federal governments or those supervised by the department.

"Hospital" means any premises, other than a mental health establishment as defined herein, operated for profit, having an organized medical staff and providing equipment and services primarily for inpatient care for two or more individuals who require definitive diagnosis and/or treatment for illness, injury or other disability or during or after pregnancy, and which also regularly makes available at least clinical laboratory services, diagnostic X-ray services and definitive clinical treatment services. The term shall include such premises providing either diagnosis or treatment, or both, for specific illnesses or conditions.

new #8 "Immobile person" means an individual who is unable to move from one location to another or has difficulty in understanding and carrying out instructions without the continued full assistance of other persons, or is incapable of independently operating a device such as a wheelchair, prosthesis, walker or cane, to exit a building.

"Maternity home" means any premises operated for profit in which, within a period of six months, any person receives more than one woman or girl, not a relative of the operator, for care during pregnancy or immediately after delivery.

"Mental health establishment" means any premises or part

thereof, private or public, for the care of individuals who require care because of mental illness, mental retardation or inebriety but shall not be deemed to include the private home of a person who is rendering such care to a relative.

"Nursing home" means any premises operated for profit in which nursing care and related medical or other health services are provided, for a period exceeding twenty-four hours, for two or more individuals, who are not relatives of the operator, who are not acutely ill and not in need of hospitalization, but who, because of age, illness, disease, injury, convalescence or physical or mental infirmity need such care.

"Person" means any individual, partnership, association or corporation operating a facility.

"Personal care home [for adults]" means any premises in which food, shelter and personal assistance or supervision are provided for a period exceeding twenty-four hours for four or more [than three] adults who are not relatives of the operator, [and] who do not require the services in or of a licensed long-term care facility but who do require assistance or supervision in such matters as dressing, bathing, diet, financial management, evaluation of a residence in the event of an emergency or medication prescribed for self administration.

"Personal care home administrator" means an individual who is charged with the general administration of a personal care home, whether or not such individual has an ownership interest in the home or his functions and duties are shared with other individuals.

"Relative" means parent, child, stepparent, stepchild, grandparent, grandchild, brother, sister, half brother, half sister, aunt, uncle, niece, nephew.

"Social service auspices" means any nonprofit agency regularly engaged in the affording of child or adult care.

Section 4. Section 1006 of the act is amended to read:

Section 1006. Fees.--Annual licenses shall be issued when the proper fee, if required, is received by the department and all the other conditions prescribed [by] in this act are met. For personal care homes, the fee shall be an application fee. The fees shall be:

Facility	Annual [License] Fee
Adult day care center	$ 15
Mental health establishment	50
[Personal care home	10
Hospital	100
Nursing home--under 30 beds	15
--over 30 but under 50 beds	25
--50 but under 100 beds	50
--100 or more beds	75
Maternity home	15]
Personal care home-- 0 - 20 beds	15
-- 21 - 50 beds	20
-- 51 - 100 beds	30
--101 beds and above	50

No fee shall be required for the annual license in the case of day care centers, family day care homes, boarding homes for children or for public or nonprofit mental institutions.

Section 5. Section 1051 of the act, amended December 5, 1980 (P.L.1112, No.193), is amended to read:

Section 1051. Definition.--As used in this subarticle--

"Private institution" means any of the following facilities by whatever term known and irrespective of the age group served:

Mental hospital, institution for the mentally defective, day care center, nursing home, hospital, [boarding home,] personal care home, and other similar institution which is operated for profit and which requires a license issued by the department.

Section 6. The act is amended by adding sections to read:

Section 1057.1. Appeals.--(a) An appeal from the decision of the department relating to the licensure or revocation of a personal care home shall not act as a supersedeas but, upon cause shown and where circumstances require it, the reviewing authority shall have the power to grant a supersedeas.

(b) If, without good cause, one or more Class I or Class II violations remain uncorrected or when the home has demonstrated a pattern of episodes of noncompliance alternating with compliance over a period of at least two years such as would convince a reasonable person that any correction of violations would be unlikely to be maintained, the department may petition the court to appoint a master designated as qualified by the department to assume operation of the home at the home's expense for a specified period of time or until all violations are corrected and all applicable laws and regulations are complied with.

Section 1057.2. Relocation.--(a) The department, in conjunction with appropriate local authorities, shall relocate residents from a personal care home if any of the following conditions exist:

(1) The home is operating without a license.

(2) The licensee is voluntarily closing a home and relocation is necessary for the health and welfare of the resident or residents.

(3) The department shall offer relocation assistance to

residents relocated under this section. Except in an emergency, the resident shall be involved in planning his transfer to another placement and shall have the right to choose among the available alternative placements. The department may make temporary placement until final placement can be arranged. Residents shall be provided with an opportunity to visit alternative placement before relocation or following temporary emergency relocation. Residents shall choose their final placement and shall be given assistance in transferring to such place.

(c) Residents shall not be relocated pursuant to this section if the secretary determines, in writing, that such relocation is not in the best interest of the resident.

Section 1257.3. Rules and Regulations for Personal Care Home.--(a) The rules and regulations for the licensing of personal care homes promulgated by the department shall require that:

draft developed by ABD

(1) Prior to a resident's admission to a personal care home, an initial standardized screening instrument be completed for that resident by the personal care home provider or a human service agency. Such standardized screening instrument shall be developed by the department. This screening will be done to determine that the potential resident does not require the services in or of a long-term care facility or whether the potential resident requires personal care services and, if so, the nature of the services and supervision necessary.

(2) In addition to the screening, each resident receive a complete medical examination by a physician prior to, or within thirty days of, admission and that once admitted, each resident receive a screening and medical evaluation at least annually.

(3) A personal care administrator refer an applicant whose needs cannot be met by a personal care home to an appropriate assessment agency. (BSS for LAMP) OBRA)

(4) Each resident be provided by the administrator with notice of any Class I or Class II violations uncorrected after five days. -not until Reg developed.

(5) All residents sign a standard written admission agreement which shall include the disclosure to each resident of the actual rent and other charges for services provided by the personal care home.

(6) For residents eligible for Supplemental Security Income (SSI) benefits, actual rent and other charges not exceed the resident's actual current monthly income reduced by a personal needs allowance for the resident in an amount to be determined by the department, but not less than twenty-five dollars ($25).

(7) A personal care home not seek or accept any payments from a resident who is a Supplemental Security Income (SSI) recipient in excess of one-half of any funds received by the resident under the act of March 11, 1971 (P.L.104, No.3), known as the "Senior Citizens Rebate and Assistance Act."

(8) A personal care home not seek or accept from a resident who is eligible for Supplemental Security Income (SSI) benefits any payment from any funds received as lump sum awards, gifts or inheritances, gains from the sale of property, or retroactive government benefits: Provided, however, That an owner or operator may seek and accept payments from funds received as retroactive awards of Social Security or Supplemental Security Income (SSI) benefits, but only to the extent that the retroactive awards cover periods of time during which the resident actually resided in the personal care home.

(9) Each resident who is a recipient of or an eligible applicant for Supplemental Security Income (SSI) benefits be provided, at no additional charge to the resident, necessary personal hygiene items and personal laundry services. This requirement does not include cosmetic items.

(10) All residents may leave and return to the personal care home, receive visitors, have access to a telephone and mail and participate in religious activities.

(11) Personal care home owners, administrators or employes be prohibited from being assigned power of attorney or guardianship for any resident.

(b) The department shall not prohibit immobile persons who do not require the services of a licensed long-term care facility, but who require personal care services, from residing in a personal care home, provided that the design, construction, staffing or operation of the personal care home allows for safe emergency evacuation.

Section 7. Article X of the act is amended by adding a subarticle to read:

ARTICLE X

DEPARTMENTAL POWERS AND DUTIES AS TO LICENSING

* * *

(d) Personal Care Home

Section 1095. Classification of Violations.--The department shall classify each violation of its regulations on personal care homes into one of the following categories:

(1) Class I. A violation which indicates a substantial probability that death or serious mental or physical harm to any resident may result.

(2) Class II. A violation which has a substantial adverse

effect upon the health, safety or well-being of any resident.

(3) Class III. A minor violation which has an adverse effect upon the health, safety or well-being of any resident.

Section 1086. Penalties.--(a) The department shall assess a penalty for each violation of this subarticle or regulations of the department. Penalties shall be assessed on a daily basis from the date on which the citation was issued until the date such violation is corrected except in the case of Class II violations. In the case of Class II violations, assessment of a penalty shall be suspended for a period of five days from the date of citation provided that, except for good cause, the provider has corrected the violation. If the violation has not been corrected within the five-day period the fine shall be retroactive to the date of citation.

(b) The department shall assess a penalty of twenty dollars ($20) per resident per day for each Class I violation.

(c) The department shall assess a minimum penalty of five dollars ($5) per resident per day up to a maximum of fifteen dollars ($15) per resident per day for each Class II violation.

(d) There shall be no monetary penalty for Class III violations unless the provider fails to correct the Class III violation within fifteen days. Failure to correct the violation within fifteen days may result in an assessment of up to three dollars ($3) per resident per day for each Class III violation retroactive to the date of the citation.

(e) A personal care home found to be operating without a license shall be assessed a penalty of five hundred dollars ($500). If, after fourteen days, a provider of a personal care home cited for operating without a license fails to file an application for a license, the department shall assess an

additional twenty dollars ($20) for each resident for each day in which the home fails to make such application.

(f) Any provider charged with violation of this act shall have thirty days to pay the assessed penalty in full, or, if the provider wishes to contest either the amount of the penalty or the fact of the violation, the party shall forward the assessed penalty not to exceed five hundred dollars ($500) to the Secretary of Public Welfare for placement in an escrow account with the State Treasurer. If, through administrative hearing or judicial review of the proposed penalty, it is determined that no violation occurred or that the amount of the penalty shall be reduced, the secretary shall within thirty days remit the appropriate amount to the provider with any interest accumulated by the escrow deposit. Failure to forward the payment to the secretary within thirty days shall result in a waiver of rights to contest the fact of the violation or the amount of the penalty. The amount assessed after administrative hearing or a waiver of the administrative hearing shall be payable to the Commonwealth of Pennsylvania and shall be collectible in any manner provided by law for the collection of debts. If any provider liable to pay such penalty neglects or refuses to pay the same after demand, such failure to pay shall constitute a judgment in favor of the Commonwealth in the amount of the penalty, together with the interest and any costs that may accrue.

(g) Money collected by the department under this section shall be placed in a special restricted receipt account and shall be first used to defray the expenses incurred by residents relocated under this act. Any moneys remaining in this account shall annually be remitted to the department for enforcing this

provisions of this subarticle. Fines collected pursuant to this act shall not be subject to the provisions of 42 Pa.C.S. § 3733 (relating to deposits into account).

(b) The department shall promulgate regulations necessary for the implementation of this section in order to ensure uniformity and consistency in the application of penalties.

Section 1087. Revocation or Nonrenewal of License.--(a) (1) The department shall temporarily revoke the license of a personal care home if without good cause one or more Class I violations remain uncorrected twenty-four hours after the personal care home has been cited for such violation or if without good cause one or more Class II violations remain uncorrected fifteen days after being cited for such violation.

(2) Upon the revocation of a license pursuant to this subsection, all residents shall be relocated.

(3) The revocation may terminate upon the department's determination that its violation is corrected.

(4) If, after three months, the department does not issue a new license for a personal care home license revoked pursuant to this section:

(i) Such revocation or nonrenewal pursuant to this section shall be for a minimum period of five years.

(ii) No provider of a personal care home who has had a license revoked or not renewed pursuant to this section shall be allowed to operate or staff or hold an interest in a home that applies for a license for a period of five years after such revocation or nonrenewal.

(b) The department shall revoke or refuse to renew the license of a personal care home if during any two-year period, the home, without good cause, on two or more separate occasions,

has been found to have violated a regulation of the department which has been categorized as Class I.

(c) The power of the department to revoke or refuse to renew or issue a license pursuant to this section is in addition to the powers and duties of the department pursuant to section 1026.

Section 8. The Department of Labor and Industry, in cooperation with the Department of Public Welfare, shall evaluate the Commonwealth's fire and safety laws pertaining to personal care homes and report back to the General Assembly and the Intra-Governmental Council on Long-Term Care established by this act regarding acceptable Statewide standards for fire safety and building codes for personal care homes. This report and recommendation shall be transmitted to the General Assembly within ~~one year~~ 21 MONTHS from the date of final enactment of this act. <—

Section 9. The Department of Public Welfare shall evaluate the costs of providing personal care and the adequacy of the personal needs allowance for personal care home residents and report its findings to the Appropriations Committees of the House of Representatives and of the Senate and to the Intra-Governmental Council on Long-Term Care. This report and recommendations shall be transmitted to the Appropriations Committees of the House of Representatives and of the Senate and to the Intra-Governmental Council on Long-Term Care within nine 21 months from the date of final enactment of this act. <— <—

Section 10. The department shall prepare an analysis of the feasibility of using funds under the Social Security Act (Public Law 74-271, 42 U.S.C. § 301 et seq.), including funds under the Medicaid Section 2176 Waiver Program, to provide case management

services. This analysis shall be transmitted to the Appropriations Committees of the House of Representatives and of the Senate and to the Intra-Governmental Council on Long-Term Care within ~~nine~~ 21 months from the date of final enactment of this act. AS USED IN THIS SECTION, CASE MANAGEMENT MEANS, IN CONSULTATION WITH AND UPON THE APPROVAL OF THE RESIDENT, TO ASSIST SUCH RESIDENT IN THE DEVELOPMENT AND IMPLEMENTATION OF AN INDIVIDUALIZED PLAN FOR ACTIVITIES AND SERVICES BOTH WITHIN AND OUTSIDE THE PERSONAL CARE HOME.

Section 11. This act shall take effect immediately.

STATEMENT OF PATRICIA MURPHY, DIRECTOR, NEW YORK CITY LONG TERM CARE OMBUDSPROGRAM, NEW YORK CITY, NY

Ms. MURPHY. For nearly 10 years I have directed the New York City Long Term Care Ombudsprogram.

A few years ago Congress mandated that the ombudsmen throughout the country pay attention to board and care homes. Some of us welcomed the opportunity. Most of us, however, received absolutely no increase in funding or increase in staff. The case examples that I cited in my written testimony and the reports that we have made available to you from our New York City Ombudsprogram show that we have tried to do our best, but we haven't done a very good job.

Last year, 93 volunteers in New York City and five professional staff members visited 100 out of 158 nursing homes and 20 of the nearly 60 adult homes. We visited about 3,000 of the 9,000 beds in New York City where there are adult home residents. My staff hates to go to adult homes for a lot of reasons. One of the reasons is, and I think it is a very natural professional reason, when they walk in they can't walk out. They get so many cases that to follow up on them takes them days and days and days. For the same reason we have difficulty recruiting volunteer ombudspeople for adult homes. It is easier for ombudspersons to pursue cases in nursing care facilities because they have more professional staff with whom to verify and resolve complaints.

About half of our 9,000 adult home residents in New York City are elderly, frail, and poor. The other half have a psychiatric disability of some kind. About half of those are also elderly, frail, and poor. Altogether they form a very vulnerable population.

When the special committees' staff asked the Ombudsprogram to to accompany them to at least one good facility and three or four others that were typical (with one of these to be poor) I said that it would be very easy to choose the good facilities as there were few of them excluding the few facilities that serve a well-to-do population. It was also easy to cluster a number of typical facilities to make their visit more efficient. The adult homes described in the report, which I haven't seen as yet, are typical of New York City proprietary adult homes. They are not, I am sorry to say, unusual. It made me ashamed on behalf of my State and the New York State Department of Social Services that Ms. Gardner commented that one of the facilities reminded her of unlicensed facilities in another State. And yet, New York State is considered to have higher standards and stiffer regulations than most other States.

The Ombudsprogram has found all of the things that other people have found. I would like, in particular to support Anne Hart's recommendations. I wish we had a model statute in New York City that is similar to the D.C. statute.

New York is considered to have higher standards than many other States. In reality the State has developed a system of "no accountability on any level." While the standards of hotel-type services and to personal care have been greatly improved in the last few years, a very small percentage of the New York State Department of Social Services enforcement effort is devoted to adult homes. With 9,000 residents in Adult Home the surveillance has

about 11 people division in the New York City office who are inspectors, many of whom also inspect the shelter system. You can imagine how much enforcement is possible.

The system of financing adult home care, which is my particular interest, with reimbursement tied to the amount of an individual's SSI check minus a personal allowance, does not link services to financing. Operators who have shown competence and creativity, and there are some, are penalized while those without scruples receive a built-in excuse. The inability of the State to set rates based on services and care needs limits enforcement potential as well.

Funding, inspecting and regulating the so-called mental health and rehabilitation services through separate mechanisms creates chaos in service provision, monitoring, and enforcement. In some instances, we suspect collusion for gain between adult home operators and mental health providers. In any event the facility operator and the support team blame each other for problems. By monitoring these systems independently, each regulator blames the other for care deficiencies, thus repeating the facility-mental health team scenario. Enforcement actions are difficult to initiate and even harder to complete in such a system of passing the buck.

To state that adult homes are financed largely through Social Security payments ignores the true cost of this care. To determine the real cost in dollars, we must add the Medicaid cost of treatment and the cost of so-called rehabilitation field teams funded through mental health and Medicaid. I believe that a comprehensive audit of these costs would demonstrate substantial waste, abuse and fraud. The hodgepodge of financing a system of accountability places the residents at greater and greater risk of abuse. The lack of standards' positive enforcement provides opportunity for fraud and abuse not seen since the early days of the nursing home scandals.

I have personally confronted operators, including two of the ones visited by the investigation team, about holding Medicaid cards. They hold the Medicaid cards and dole them out supposedly as needed. The New York State Department of Social Services tells us that, while operators cannot force residents to give them the Medicaid cards, it is okay for them to hold them because "after all people do lose their cards". I recommend both short-term and long-terms strategies to provide us all the assurances that frail residents are receiving decent care and treatment.

Congress should establish Federal standards for board and care facilities and should not fund them through individual direct payments. Congress should commission an investigation and study similar to the Institute of Medicine study which supported OBRA '87. In the immediate future, however, Congress should declare board and care residents a protected class under Federal law and forbid, absolutely forbid, owners or employees from becoming representative payees or holding Medicaid cards.

Finally, a modest addition to the ombudsman program's funding would materially assist the protection of adult home residents.

I thank you.

[The prepared statement of Ms. Murphy follows:]

Testimony of
Patricia H. Murphy
Director
New York City Long Term Care Ombudsprogram

My name is Patricia H. Murphy. For nearly ten years I have directed the New York City Long Term Care Ombudsprogram. The Ombudsprogram is mandated through the Older Americans Act and, in New York City, is funded through a contract with the New York City Department for the Aging.

The Ombudsprogram functions under the regulations promulgated by the New York State Office for Aging with leadership provided by the State Long Term Care Ombudsman, David R. Murray.

In New York City the Ombudsprogram recruits, trains, places, and supervises volunteer Ombudspersons who spend four to six hours each week in assigned nursing homes and adult homes. In adddition to supervising volunteer Ombudspersons, the professional staff investigates and resolves complaints and problems which residents, families and friends report about facilities which are not visited regularly.

There are 158 skilled nursing and health related facilites totalling nearly 40,000 beds, and 58 adult homes with approximately 9,000 beds in the five boroughs of New York City. In fiscal year 1987-88 93 volunteers and five paid staff visited 100 nursing homes (25,372 beds) and 20 adult homes (3,469 beds). They spent more than 15,340 hours in these facilities. In that one year, the program handled more than 1,000 complaints. Two-thirds of these complaints were reported by residents themselves or were problems observed by the Ombudspersons on their regular visits.

My remarks today will focus on the adult home industry and its regulations and financing.

Approximately 50% of the 10,000 plus people who live in Adult Homes in New York City are frail, old, and poor. Many have chronic debilitating medical conditions which prevent them from living independently but which do not require nursing supervision.

The other half of the Adult Home population have extensive psychiatric histories. Of these, half again are frail, old, and poor. The remaining 25% or so are physically capable of self-care but are psychiatrically disabled.

All three populations are badly served by the adult home system.

Those who are elderly and physically frail require a supportive environment which will maintain their physical well-being and promote their social and mental growth. They receive poorly-cooked food,

activities which negate their intellectual and social abilities, and a nearly total lack of social services or case management. With lamentably few exceptions the best they can hope for is to be patronized; at worst they are terrorized.

The situation for those with psychiatric histories is even more grim. The older people among them have spent long years in state institutions and thus have no idea how to exercise their rights. Many owners want this resident, most often a woman, because she is passive and easily intimidated, fearing to be returned to the state hospital.

The younger more aggressive, often male, resident tends to express his frustration through inappropriate behavior. In my opinion we should be grateful to these residents for drawing attention to the dismal conditions under which they are forced to live. However, his fellow residents are often frightened by his loud protests and can bear the brunt of his anti-social tendencies.

It is not enough to grant people rights; those who need to live in protective settings also need to be protected in these settings.

When some years ago, Congress required the Ombudsprograms to assist residents of adult homes, many of us welcomed the opportunity. Unfortunately, as with other aspects of care, and especially, "de-institutionalization", most of us received no additional resources.

The few case examples I am citing today, and the reports our office has made available to you, are illustrative of the norm, not the most egregious examples.

CASE EXAMPLES

An 85-year old man who lives in a proprietary adult home restricted to elderly people without psychiatric histories, called to ask us if the proprietor could rent his room for the 10 days he visited his children during Passover; he paid his rent during that time, but the previous year the owner had rented his room anyway. We warned the owner not to do this and reported him to the monitoring agency. He was not cited for this violation. Every year since than, we call the facility prior to Passover to remind the owner we are still watching. The resident always calls to thank us.

A 70-plus man in a non-profit home was referred to us by the Legal Aid Society, 1685 East 15 Street, Brooklyn, N.Y. 11229, with a request that we coordinate with a pro bono attorney. The facility was trying to evict him saying he had pushed a woman resident who had then fallen. The man, who is of limited intelligence, had no history of violence and no one had seen the "push". While eviction procedures were instituted, this shy, sweet resident was being punished by being isolated - even required to take his meals in his room. Again, the facility was not cited.

A couple who had been residents of an adult home left owing the facility money. The owner tracked them down to their apartment, and demanded the money. When Mr. Green asked him to leave because Mrs. Green was getting upset, the owner, a large man, picked Mr. Green up and slammed him against a wall causing a compressed shoulder fracture. Only our persistent efforts caused the police to investigate and the District Attorney's office to prosecute; the owner was allowed to plea bargain the assault charge down to a misdemeanor. The New York State Department of Social Service, Department of Adult Services, despite our early notification to them of this case did nothing. This man is still the owner and administrator of record at this facility.

In this particular facility the case manager admitted openly to a legal aid attorney and me that he "kept" residents Medicaid cards. A few courageous residents secured their drug print-outs and told us and the Medicaid Fraud Abuse Unit that drugs and supplies which they had never received nor needed, were charged to their Medicaid numbers. The facility deals with a pharmacy some distance away, and had photo-copied residents' cards.

The incidents of residents' property searched, disposed of, and residents' personal allowance mis-appropriation are too numerous to give more than one example. A 40 year old woman complained to us that the facility's owner had taken many of her possesions including a necklace which was of great sentimental value. After Jeffrey Abrandt, the experienced attorney-in-charge of Brooklyn Legal Aid for the Elderly, wrote the facility a strong letter, I received a letter on the facility's letterhead asking us to cease our intervention. This letter bore the resident's name. She had neither written nor signed the letter but was next in line for a transfer to a group home. Terrified that the owner in some way would block her only opportunity, she asked us not to pursue the return of her belongings any further.

In January 1989, Kathy Gardner, Staff Director, and Peter Reinecke, Research Director, of the House Select Committee on Aging, asked me to select four facilities, one good and three typical, to visit on January 23, 1989. It was easy to choose the good facility, Madison-York, a proprietary facility in Queens.

The other three facilities were chosen because they were located within a small geographic area. All are proprietary and each owned by different people. In one we had a newly placed Ombudsperson. The attached letter I wrote, as well as Ms. Gardner's and Mr. Reinecke's report describes much of what we found. In particular I would like to draw your attention to the administrator's comments. After a lecture about the rehabilitation potential of the residents in his facility which exposed his total ignorance of modern treatment and the rehabilitation potential of psychiatrically disabled residents, this man who is negotiating to purchase the facility, stated that he knew he violated the regulations but knew also that the State of New York would not close him down because they have no place else to house "these people".

He admitted keeping Medicaid cards, serving as a representative payee and holding social security checks to be signed and turned over by the residents. He shamelessly admitted urging doctors to prescribe medication three times a day so that it could be distributed with greater administrative ease.

Unfortunately this administrator and this facility are typical in action and attitude to most we have encountered.

STANDARDS AND ENFORCEMENT

New York State is considered to have higher standards than many other states. In reality the State has developed a system of no-accountability on any level. While the standards of hotel-type services and personal care have been greatly improved in the last few years, a very small percentage of the New York State Department of Social Service enforcement effort is devoted to adult homes.

The system of financing with reimbursement tied to the amount of an individual's SSI check does not link services to financing. Operators who have shown competence and creativity are penalized while those without scruples receive a built-in excuse. The inability of the State to set rates based on services and care needs, limits enforcement potential as well.

Supporting the so-called mental health and rehabilitation services through separate mechanisms creates chaos in service provision, monitoring, and enforcement. In some instances we suspect collusion for gain between adult home owners and mental health providers.

By monitoring these systems independently each regulator blames the other for care lacks, thus repeating the facility/mental health team scenario. Enforcement actions are difficult to initiate and even harder to complete in such a system of "passing the buck".

FINANCING

To state that adult homes are financed largely through social security payments ignores the true cost of this care. To determine the real cost in dollars, one must add the Medicaid costs of treatment and the cost of the so-called rehabilitation teams, funded through mental health and Medicaid. I believe that a comprehensive audit of these costs would demonstrate substantial waste and abuse.

CONCLUSION

The hodge-podge financing and system of accountability place the resident at greater and greater risk of abuse. The lack of standards and paucity of enforcement provide opportunities for fraud and abuse not seen since the early years of the nursing home scandals. As nursing home, hospital and psychiatric treatment beds are severely restricted and priced out of the market, the adult home is increasingly used as an alternative placement for the, so called, less disabled.

In New York State a recent statute allows a limited number of home care services to be provided to residents who might otherwise need residential health care facilities. This provision is frightening under the circumstances.

RECOMMENDATIONS

I recommend both short and long term strategies to provide us all with the assurances that these frail residents are receiving decent care and treatment and that we taxpayers are paying for appropriate services rendered.

Congress should establish Federal standards for board and care facilities. In order to assure the most sensible standards without overregulation, Congress could commission an investigation and study similar to the Institute of Medicine study which supported OBRA '87: The Nursing Home Reform Law.

This study should focus on developing both standards of care and new principles of financing that care.

In the immediate future, however, Congress should declare board and care residents a "protected class" under Federal law, forbid owners or employees from becoming representative payees or holding Medicaid cards. A modest addition to the Ombudsprograms funding would materially assist the protection of adult home residents.

The CHAIRMAN. Thank you, Ms. Murphy.

Let me say—I'm going to break the chain here just a moment. Two days ago on the Senate floor, Senator Bob Graham, of Florida, had the floor for almost four hours waiting to make a statement on the Tower nomination. Senator Graham exemplified, I think, the greatest amount of patience and perseverance I have ever seen and he kept yielding one minute, ten minutes, three minutes, or whatever, as he stood there four and one-half hours to make his speech. If I could paraphrase Winston Churchill, I would say that never had so many stolen so much from one Senator in stealing his time on the floor. He has also been here three times this morning waiting for an opportunity to make a statement or to ask a question, so I am going to yield right now to Senator Graham.

STATEMENT OF SENATOR BOB GRAHAM

Senator GRAHAM. Mr. Chairman, I appreciate that very generous statement. I don't want to contribute to the mental health problems or anxiety of this audience further, so I would like to submit for the record an opening statement which I have, as well as ask unanimous consent to file for the record an article which appeared in the Orlando Sentinel on February 3, relative to the issue of board and care in our State of Florida.

The CHAIRMAN. Thank you, Senator Graham, and without objection they will be placed at the appropriate part in the record.

Senator GRAHAM. I want to commend you for having organized this excellent series of panels and to each of those who have participated, it has been very instructive. I commend you for sharing your experience with this committee so that we in turn can be more effective in shaping appropriate Federal policy.

[The prepared statement of Senator Graham and its attachments follow:]

BOB GRAHAM
FLORIDA

United States Senate
WASHINGTON, DC 20510

STATEMENT BY SENATOR BOB GRAHAM
U.S.Senate Special Committee on Aging
U.S. House Subcommittees on Health and Long-Term Care
and Housing and Consumer Interests
March 9, 1989

BOARD AND CARE: A FAILURE IN PUBLIC POLICY

Mr. Chairmen, I appreciate the opportunity to participate in this timely and important hearing on board and care homes.

Board and care homes, or ACLFs (adult congregate living facilities) as they are called in Florida, fill an important role in the continuum of care available for our nation's older Americans. In Florida alone, there are 1,479 licensed facilities that have over 59,000 beds. Nationally, it is estimated that over 1 million elderly, disabled and mentally ill, currently call a board and care facility home.

There is much we do not know about this industry that has grown in Florida over 49 percent over the last four years. There are many homes existing in neighborhoods that are not licensed or sanctioned by states. Since the definition of what a board and care home is varies from state to state, it is difficult to consistently classify these facilities. We know that many times the residents have very low incomes, maybe just a monthly SSI check, and that they may have very high service needs. The size of the home can vary tremendously as well. In Florida, an ACLF can range in size from a four bed home to a huge retirement community.

These residences can provide essential assistance and a sense of community, and in some cases provide a middle ground between a nursing home and independent living for the elderly resident. But while the nursing home industry has in place guidelines and regulations--the board and care industry, which takes in over $400 million a year in Florida, has gone widely unregulated and the laws that exist have not been enforced.

Florida is one of the states that has regulations in place requiring some minimum standards on safety and sanitation and has state laws on what kind of resident and what kind of care the home can provide. Florida also supplements the SSI checks. And in Florida, the state legislators are discussing further refinement of the legal definitions of board and care homes.

But what we have done on the federal and state level has not been enough.

What is the disturbing, ugly part of this business we will hear today: the abuse of older persons handicapped and the mentally ill in a supposedly sheltered environment. The kinds of shocking stories we have seen on the evening news and read about in the paper, are very frightening examples of the egregious violations of trust and decency in what should be a safe environment.

The Orlando Sentinel in December of last year did a superb investigative series on ACLFs, or board and care homes in Florida. The reporters found many horror stories of neglect and abuse--even death. Safety, sanitary and dietary standards, were at best, minimal. The 1500 complaints investigated by the Long-Term Care Ombudsman Council from 1987 to 1988 most often centered on inadequate supervision, insufficient amounts of food, bad food, inappropriately placed residents, and deposits or money not refunded.

This is unacceptable. We need very strong regulation of this industry. We have both federal and state responsibility for regulating and enforcing laws in this industry that continues to grow and serve an increasing number of frail elderly and mentally ill people across the country.

Not only can many Floridians not afford nursing home care, in many areas there are not enough nursing beds. Over 3 million people are over 65 in Florida. The demand for board and care homes will continue to increase; in the last four years the ACLF industry has grown over 49 percent.

Our role as federal legislators is clear:
o We need a national, consistent definition of board and care so that states can collect data and share it;
o As federal legislators, we need to work with our colleagues in the states to share information and encourage tougher laws and sanctions for system abusers;
o We need to set a national minimum standard for the kind for care and safety in board and care homes.

Older adults and their children need to play a strong watchdog role. We need to educate and inform consumers in our states to check for licensing standards and carefully tour the home, talk to staff and ask for the latest results of inspections. Read the contracts carefully before signing, especially the fine print. Finally, make a visit to the home unannounced, and check with the state regulators to look up the home's record.

I commend the Chairmen for this important hearing and I urge my colleagues to work together to take expedient action on standards and defining this industry, so that we can effectively regulate it.

The Orlando Sentinel

Friday, February 3, 1989

FLORIDA'S FORGOTTEN ELDERLY

A policy of neglect endangers thousands of residents in personal care homes.

Herta Johnson sits alone in the TV room at Ocean View Manor, Daytona Beach. It is the main gathering place there

The state nods at abuse, even death

By Craig Dowers and Sandra Mathers

The state of Florida is licensing neglect, abuse and death.

The faces of the victims are wrinkled, and they are old.

By the thousands, Florida's elderly residents are moving into personal care homes that have been stamped with the approval of the state's Department of Health and Rehabilitative Services.

But a license from HRS is no guarantee that a personal care home provides decent care. The Orlando Sentinel found in a seven-month investigation of the agency and its oversight of these homes.

HRS regulates 1,479 personal care homes with room for 39,721 residents, more people than are in nursing homes. These homes, which take in more than $480 million a year, are licensed to shelter and supervise frail elderly people.

Year after year, HRS has identified problems throughout the industry, but it has failed to use its broad authority to correct them.

And year after year, the agency has renewed the licenses of homes where its investigators have confirmed cases of abuse or neglect.

That's what happened at Green Acres Retirement Center in Orlando. Joy Clark died in 1985 after staying in the home, which was licensed and inspected by HRS. She had been neglected, agency investigators said.

After eight months in Green Acres, the 84-year-old retired homemaker was rushed to the hospital. She was dehydrated, malnourished and covered with draining bedsores.

Even after Clark's death, Green Acres stayed open for almost three years with new licenses from HRS. By that time, 82-year-old Lola Barnhardt — also emaciated and covered with infected bedsores — had died at the home.

She, too, died of neglect, investigators said.

The home's operators were charged with neglect in March. They have pleaded not guilty.

Margaret Hamilton died after staying in an illegal personal care home in Orlando that HRS knew about for seven years but neither shut down or forced to get a license.

In February 1988, when the 83-year-old great-grandmother arrived at the hospital from Ruth Robertson's unlicensed home, she was in a coma. She had infected bedsores and blood poisoning. She weighed only 70 pounds — 30 pounds less than she had two months before.

Robertson's neglect contributed to Margaret

Please see HOMES, 2

Abuse accusations rarely end up in court

Despite thousands of reports, state prosecutors are slow to bring charges

By Craig Dezern
Of the Sentinel Staff

The witnesses accused Gloria Woodard of abusing three confused, elderly women at a personal care home.

A nurse: *I saw her pull her ears, I saw her punch her in the back with her fist.*

Another nurse: *Jimmie was engaged in emptying the trash. . . . As she bent over, Mrs. Woodard took her knee and gave her a bump in the behind. She tumbled over the trash cans and hit the side of the refrigerator. Her glasses fell off.*

I noticed she had about an inch and a half long gash on her nose where she had hit either the refrigerator or one of the small trash cans.

An elderly resident: *She would punish them. Well, she'd slap them or knock them down or fight them or something like that and sit them down hard — wouldn't let them go to the bathroom if she thought they went too many times.*

Those witnesses and others told police and attorneys in sworn statements that Woodard had abused three residents in her Winter Park personal care home late last year. But they will never tell their stories in court.

Although Winter Park police charged Woodard with battery and abuse, a prosecutor in the Orange-Osceola County State Attorney's Office dropped the charges.

"There was no abuse at all," Woodard said recently. "The whole thing was a fiasco. I think it was the worst period of my life, because I'm not that kind of person."

People who are accused of abusing the elderly in Florida's personal care homes rarely are taken to court.

From January to September this year, 14,800 cases of abuse of the elderly were reported to the Florida Department of Health and Rehabilitative Services. The agency couldn't say how many of the cases were in personal care homes. More than 1,400 were confirmed by state investigators.

HRS, however, rarely takes action. And state attorneys take even fewer cases to court.

From January 1986 to January 1988, HRS investigators confirmed at least 35 cases of abuse or neglect in personal care homes in Orange, Seminole, Osceola and Brevard counties. But state attorneys pursued charges in only one case.

Abuse of the elderly "does not seem to instill the sense of outrage that child abuse does," said Rob Bridger, administrator of HRS's Aging and Adult Services office in Orlando.

No assistant state attorney in Central Florida specializes in prosecuting elderly abuse cases, Bridger said.

"From my experience over the last 10 years, the responsiveness varies with the sensitivity of the assistant state attorney," he said. "We would like to see that sensitivity across the board."

Tim Hetz, a spokesman for the Orange-Osceola State Attorney's Office, said the office can't afford to have a prosecutor specializing in abuse of adults.

Wendell Perdue, chief investigator of the office, said abuse cases from these homes are difficult to prosecute because there often are no witnesses. "A patient says someone slapped her, and the other person says, 'I did no such thing.'"

The relationship between HRS and state attorneys' offices is shaky. A 1986 study of HRS's Adult Protective Services staff members showed that one in five described the relationship as poor. More than a third didn't know if any of the cases they sent to state attorneys had been prosecuted.

> "
> *The first three months my grandmother lived there, her spirit was broken. They tied her to the bed, and I was called at all hours to calm her.*
>
> — Peany Schwahl

In the same study, state attorneys' offices reported having almost no contact with Adult Protective Services for as long as three years.

Winter Park police have statements from witnesses such as Grace English, an 88-year-old woman who lived at the Woodard home for nearly a year.

English, who has white, fluffy hair and a pale, sagging face, speaks in a quavering voice and becomes teary-eyed when she remembers her stay at Personal Care with Dignity. She wouldn't tell a reporter what happened, but she gave a detailed sworn statement to police.

She said Woodard would become angry with the other residents, who had become forgetful and confused. Woodard slapped them, pulled at their ears and swore at them, English said.

Two nurses who visited the home, Anne Garner and Georgia Simpson, backed up her story in sworn statements. HRS investigators gave statements about bruises on the women that appeared to be caused by abuse.

Peany Schwahl's grandmother, Blanche DiCrescenzo, was one of the victims, police said.

"The first three months my grandmother lived there, her spirit was broken," Schwahl said in an interview. "They tied her to the bed, and I was called at all hours to calm her."

DiCrescenzo, who had been forgetful but still feisty, was medicated and lethargic. She was bloated. She had been to the hospital only once in her life, but now she was constantly at the doctor's office or the emergency room.

"My grandmother would tell me things about getting hit, but I just didn't take it into account," Schwahl said. She tried to blame the medicine or her grandmother's fading mind.

"I truly believed I was doing the best thing for my grandmother," she said. "That's what bothers me."

Now she finds it incredible that the state attorney would refuse to prosecute.

Assistant State Attorney Fred Lauten, who reviewed the case, explained: "The legal custodians or guardians of the victims indicated they didn't wish to pursue prosecution." Besides, "the victims are pretty difficult to talk to."

The best plan, Lauten said, would be to throw the case back to the HRS licensing office. "Their burden of proof is a lot lower than our burden," he said.

Abuse investigators removed all but one client from Woodard's home, and licensing officials told her she could take in no more residents.

Connie Cheren, chief of the HRS licensing office, said she may be able to deny Woodard her license to operate the home when the state hears the case.

Still, Cheren is concerned that Lauten dropped the criminal charges.

"He's saying, 'Fine, take her business away from her, and that's enough penalty,'" she said. "That's the judgment he's making."

Woodard denies that any abuse took place in her home. She said the nurses who later accused her had performed poorly at her home and were worried that she would complain. English, she said, "will say anything to get attention."

Although HRS can't force a state attorney to prosecute a case, the agency has its own arsenal of punishments. The agency's licensing office can levy fines, prevent a home from accepting new residents or even shut down a home by revoking or denying its operating license.

But even in some serious cases of abuse or neglect, those powers have not been used.

Blanche DiCrescenzo told of being hit at the Woodard home, but there was no prosecution. She's shown with her great-grandsons.

HOMES

From 1

Hamilton's death, HRS investigators said.

Nearly three years after she died — seven years after HRS inspectors first learned about the illegal home — Ruth Robertson is still in business. Robertson said she did not neglect Hamilton and doesn't need a license.

The deaths of Joy Clark, Lois Burnhardt and Margaret Hamilton show the worst that happens when HRS does not aggressively police a home. Such weak enforcement occurs, the *Sentinel* found, because the agency is in disarray and unable to keep up with the boom in personal care homes.

■ More than 4,000 people living in these homes are so frail or seriously ill that they need the medical care that only a hospital or nursing home can give. They should not be in personal care homes, which by law can provide no medical treatment.

■ Hundreds of personal care homes operate illegally, without licenses and without the supervision of HRS inspectors. But state attorneys in Central Florida have not prosecuted a single illegal operator for that felony, HRS supervisors said.

■ A gap in state law lets convicted criminals work in these homes. In Brevard County, for instance, a woman who spent two years in prison for abusing an 81-year-old man at a personal care home may again be working with the elderly, HRS investigators believe.

■ From January 1986 to January 1988, HRS investigators confirmed 35 cases of abuse or neglect in personal care homes in Orange, Seminole, Osceola and Brevard counties. But state attorneys pursued charges in only one case.

■ The state requires more training of hairdressers than it requires of the people who operate personal care homes. A home operator need only be 18 years old, have a high school education and have no criminal history or record of abuse confirmed by HRS.

■ In the past four years, HRS inspectors have found thousands of potentially harmful violations of state regulations in the 210 personal care homes in Orange, Seminole, Osceola, Lake, Brevard and Volusia counties. Often the same homes are cited for the same problems year after year. Yet only a handful of homes has been forced out of business.

■ The power to levy fines against homes with violations is one of the best enforcement tools HRS has, advocates for the elderly say. But of the 67 fines imposed on Central Florida homes since 1985, the agency has collected in full only 21. A dozen were reduced, and 34 — some as old as three years — were never collected.

■ The state requirements for these homes allow one person — even a cook or night watchman — to care for an unlimited number of residents.

■ In the past year, financial exploitation in these homes was the No. 1 complaint to the state's top advocate for the elderly. But HRS investigators rarely turn those cases over to prosecutors.

■ The monthly fee Florida pays home operators to take care of the state's indigent residents is $300 less than the actual cost of care. As a result, those poor people live in some of the worst homes.

■ The HRS inspectors who monitor personal care homes in Central Florida have no medical schooling. They have no standardized training and no written operating policies to guide them.

■ The problems in some homes are so severe and have existed for so long that HRS last year compiled an "Ugly List" of the worst. Seven of the nine Central Florida homes on the list are still in business.

In its investigation of HRS, the largest state agency in America, the *Sentinel* reviewed thousands of pages of public documents: annual inspection reports for all 210 homes in six Central Florida counties, complaints against the homes, internal HRS memos and studies published by the agency. More than 100 people — including advocates for the elderly, home operators and state officials — were interviewed.

The *Sentinel* also found many personal care homes that provide good care for their residents. But experts say few consumers understand how to choose a high quality home.

Florida's laws governing these homes are among the strongest in the country.

The state's legislation has been a national model, said Barbara Frank of the National Citizen's Coalition for Nursing Home Reform in Washington, D.C. But that doesn't mean that bureaucrats have put those laws to work protecting the elderly.

"They do have a lot on the books, but getting the political machinery working on it is difficult," Frank said. "I know that's an area where advocates have expressed their concern.

"Your state has put into place an excellent set of regulations, and if you don't use that then it is the fault of government. It makes it even worse if you don't use what you've got."

'88 statistics

Personal care homes in Florida

Personal care homes	Beds
1984	39,500
1988	59,721

Nursing homes	Beds
1984	46,000
1988	59,379

Average occupancy rate:	75%
Total in personal care homes:	44,250
Average monthly charge:	$780
Money taken in annually:	$419,490,000

Personal care homes in Florida	1,479
With 16 or fewer beds	917 (62%)
With 17 or more beds	562 (38%)
Total licensed beds in Florida	59,721
Personal care homes in Central Florida	210
With 16 or fewer beds	138 (66%)
With 17 or more beds	72 (34%)
Total licensed beds in Central Florida	8,522

County breakdown

	Personal care homes	Beds
Brevard	13	855
Lake	23	1,078
Orange	80	1,619
Osceola	8	289
Seminole	21	1,260
Volusia	65	3,421

That is exactly what has happened, say the leading advocates for the elderly, the Florida Long-Term Care Ombudsman Council. In a 1987 report, the council described a spineless HRS licensing office that is "the laughingstock of the industry."

Even leaders of the personal care home industry worry that HRS isn't strict enough.

"The state has to get rid of the crummy homes," said Karen Torgeson, executive director of the Florida Association of Homes for the Aging. "It ruins it for us. We wouldn't have all those regulations if it weren't for those homes."

HRS is working on the problem, said Connie Cheren, director of the agency's licensing office. In 1988, she has refused to renew more licenses than in the previous three years combined.

Never has there been a more crucial time to bring the personal care home industry to order.

Florida ranks first in the nation in the percentage of old people in its population. More than 3 million — or 25 percent — of the state's residents are 60 or older. By 2000, nearly 4 million residents will be 60 or older. And the fastest growing segment of Florida's population is 85 and older.

Those elderly Floridians are increasingly choosing personal care homes — which range from small, private residences in neighborhoods to large buildings owned by corporations — as an alternative to nursing homes.

When aging bodies have become too unreliable to trust alone, but not so sickly that they need 24-hour-a-day nursing care, a personal care home can be the logical choice.

This year, for the first time ever, there are more beds in personal care homes — 59,721 — than in nursing homes — 59,379. The number of beds in these homes — officially called Adult Congregate Living Facilities — has grown by 49 percent in the past four years.

In Central Florida, alone, personal care homes are licensed to care for 8,522 people. Quietly, and without much public notice, the homes have become big business.

It wasn't always so, said Margaret Jacks of Tallahassee, the first HRS director of Aging and Adult Services. In 1975, Jacks helped write and put into place the first state regulations for personal care homes.

Before then, she said, the homes had been the winter roosts of aging snowbirds.

"A lot of them were small homes, privately run homes," said Jacks, now 80 and still an outspoken advocate for the elderly. The owners "were not sophisticated. They were people who were trying to make a living taking in old people."

The first laws did not anticipate having people who were sick, Jacks said. But the clientele of these homes grows older and sicker.

HRS began monitoring personal care homes in 1975, when there were only half as many as today. Within five years, the agency realized that it had severe problems policing the industry.

A 1980 report by the House HRS committee found the following: Each year more than 100 cases of abuse in personal care homes were reported. Operators were poorly trained. State inspectors were overworked.

Those problems still exist, and more have been added.

Gregory Coler, the HRS secretary, acknowledges that his agency has troubles. But he points to improvements in the past year, such as the more effective use of moratoriums, which prevent a home from accepting new residents until problems have been fixed. More progress is on the way, he says.

"We've got our eye on the target," Coler said. "I think we understand the problem. I think we have begun to move in the right direction, and we want to get there as quickly as possible."

Last year, Cheren took over as director of HRS's licensing office.

"Everybody, when I came down here, said what problems [personal care homes] were," Cheren said in a recent interview. "I saw that when I went out. I mean, it was just obvious."

Personal care homes are not nursing homes

By Craig Dezern
OF THE SENTINEL STAFF

Definition

Personal care homes are not nursing homes. By law they cannot give medical care. Instead, personal care homes offer supervision. The staff of a personal care home can make sure that residents are taking their medicine, are eating regularly, and are staying healthy. The staff may also help frail residents with the simple tasks that can become difficult with age — eating, bathing, grooming and dressing.

Nursing home: Two simple words that call to mind a ready image of old folks with walkers or wheelchairs and a staff of women in starched white uniforms.

Adult congregate living facility: A mouthful of bureaucratic jargon that calls to mind nothing. And the layman's synonym — personal care home — is just as vague.

Seven of 10 Floridians have never heard the term adult congregate living facility or ACLF, according to a recent survey by the Florida Health Care Association. And though more than half of those surveyed have visited a nursing home in the past 10 years, only 1 percent have visited a personal care home.

Of such public ignorance is born the temptation to push personal care homes under the umbrella term of nursing homes. Both, after all, provide food and shelter for the frail elderly.

Telephone companies make the mistake all the time. Central Florida yellow pages are filled with personal care homes advertising under the "nursing home" heading. Such ads violate a state law that prohibits personal care homes from calling themselves nursing homes.

Increasingly, elderly Floridians are choosing to live in personal care homes, which are often cheaper and cozier than nursing homes. The number of personal care home beds has increased from 39,500 to 59,721 in the past four years.

But they are not nursing homes, and the distinctions are important.

State studies show that thousands of people in personal care homes are so sick that they need the care that only a nursing home or hospital can provide.

"If people are going to choose an adult congregate living facility, they need to realize it's not a health care facility," said Mary Ellen Early of the Florida Association of Homes for the Aging. "They shouldn't choose it just because they're fearful of the whole nursing home concept."

People who are too sick to live in a personal care home should be stopped from moving in by a medical screening, she said. If they aren't, then they may face a second move — to a hospital or nursing home.

"And it can be even more difficult to make that second change," she said.

People can avoid problems by understanding the basic differences between personal care homes and nursing homes:

■ By law, operators of personal care homes cannot provide the skilled, 24-hour-a-day medical care that a nursing home offers. Instead, the staff of a personal care home helps residents with their daily activities — eating, bathing, grooming and dressing.

Residents must be able to take their own medication. If they cannot, the personal care home should employ a licensed nurse to help them do so or transfer the residents to a nursing home. The home's staff can only remind the residents to take their medicine or help them remove stubborn caps from the bottles.

Residents of personal care homes are allowed to employ visiting nurses to give them any medical treatment they require. Under a new regulation, personal care homes can be licensed to provide limited nursing services such as changing colostomy bags, dressing minor wounds or applying hot compresses.

■ The residents of a personal care home must meet minimum health requirements.

Before moving to a home, each resident must undergo a physical examination. A doctor must certify that the resident's needs can be met without medical care.

A resident may stay in the home during a brief illness that requires continuous nursing care but must leave if such care is necessary for more than seven days.

■ Personal care homes usually cost less than nursing homes, but neither Medicaid nor Medicare will foot the monthly bill.

The average monthly fee at a personal care home is $730, according to a new study by the Florida Department of Health and Rehabilitative Services. Nursing home residents can expect to pay an average of $1,820.

■ Personal care homes range in size from "mom and pop" houses with a half dozen residents to corporate-owned centers with more than a hundred.

Regulated only since 1975, many personal care homes began as boarding houses for elderly tourists or retirees. For that reason, experts say, they sometimes offer a more homelike setting.

■ Personal care homes are regulated only by the state. Nursing homes are governed by state and federal laws because their residents can qualify for money from federal programs.

The average personal care home resident

White (89%)
Female (78%)
Widowed (58%)
Age: 82

Time in home: 7 years

Income: $329 to $1,500 a month

Daily activities: Most can do these things without help — bathe, dress, eat, walk outside, use a telephone.

Illnesses: Most frequent condition is arthritis, followed by heart disease, bone disorders or injuries and high blood pressure.

Too ill for home, she wasted away

By Craig Dezern
OF THE SENTINEL STAFF

Irene Dodd lay dying in a bed where she didn't belong.

Senile, nearly blind and deaf, plagued with bedsores, Dodd was far too sick to stay at Country Manor Rest Home in Port Orange.

It was against the law for Country Manor to keep Dodd in the personal care home. Such homes are not nursing homes nor are they hospitals. They are not equipped to provide medical care, and their staffs are not trained or authorized to care for sick residents.

State bureaucrats, charged with enforcing that law, knew that the 83-year-old widow was wasting away. Yet they failed to move her to a nursing home or hospital where she could have received the medical care she needed. Instead, they quibbled for four months until Dodd solved the problem.

She died.

Records from a state licensing office in Jacksonville tell the story of an agency slow and reluctant to enforce its own laws:

The day is June 18, 1985. Country Manor is cited for violating state regulations by housing a resident who needed medical care that a personal care home is not authorized to provide.

In response, operator Fred Heinen files a health assessment form from Dodd's doctor. The doctor notes Dodd's deteriorating condition — her incontinence, hypertension, hypothyroidism, osteoarthritis and heart disease. Dodd needs help taking her medicine, moving from the bed to a chair, eating and dressing.

She needs the daily care of a skilled nurse, the doctor writes. By law, personal care homes can't provide that care. But he says Dodd can stay at Country Manor, her home for the past two years, with the help of a visiting nurse.

That evaluation does not sit well with Bonnie Baxter, a nurse who works for the licensing office of the state Department of Health and Rehabilitative Services.

In a letter to licensing supervisors in Jacksonville, Baxter points out that the doctor has a conflict of interest. He is a resident at Halifax Medical Center and under the supervision of Dodd's son, Richard.

Richard Dodd wants his mother to stay at Country Manor, Baxter writes, and the resident "doesn't wish to rock the boat."

(In a recent interview, Richard Dodd explained why he wanted his mother to stay at Country Manor. Her condition was terminal, he said, and she was comfortable in Heinen's care, where she had been for about six years.)

And although Heinen has not forced Dodd to move out, Baxter writes, he "is concerned that Ms. Dodd may, at some point, become dehydrated, etc., creating a bad legal situation for him."

She closes her letter with a feeble suggestion that Dodd be moved from the home:

"Regrettably, I'm unable to recommend that Ms. Dodd remain in the ... home on the findings. However, I do respect Dr. Dodd's wishes for his mother to remain there. This is clearly a case of [the licensing office] being placed in a no-win situation."

On Aug. 14, 1985, Baxter completes her own examination of Dodd. She concludes that the woman is far too sick to stay at Country Manor.

Five days later, Baxter writes another letter to licensing supervisors detailing why Dodd must leave the home. The visiting nurses no longer visit, she writes, and the staff of the home is not large enough to provide the 24-hour-a-day care that Dodd's flagging health demands.

The information collected by Baxter is sent to a medical review team in Jacksonville.

On Sept. 11, 1985, Amy Jones, then director of the HRS licensing office, writes to Heinen:

"The medical review team has determined that Ms. Irene Dodd exceeds the level of care at any ACLF [personal care home] and is inappropriately placed.

"We would like to caution you that ... retaining residents who have been evaluated as in need of care that only authorized health care facilities may provide could lead to a very dangerous and life-threatening situation."

But a month later, Dodd is still there.

The final document in the state's record of Irene Dodd is dated Oct. 14. It's a handwritten note from inspector June Frye to her boss, Ivan Owen:

Ivan —

Irene Dodd died on 10/11/85 — 5:00 p.m.

This is the lady at Country Manor we discussed on Thursday 10/10/85. They did get nurses around the clock. When I left there at 3:30 p.m., the first shift nurse was reporting.

June

Where to call

Here's where you can call if you need information about a personal care home or need to report problems in one of them:

Office of Licensure and Certification
This branch of the Department of Health and Rehabilitative Services inspects the homes annually. In Orange, Seminole, Brevard and Osceola counties, call the Winter Park office at 407-647-7010. In Lake and Volusia counties, call 904-358-6046.

Long-Term Care Ombudsman Councils
These watchdog groups tour each home annually and assist consumers who encounter trouble there. In Orange, Seminole, Brevard and Osceola counties, call Marie Reyes at 407-423-6114. In Lake County, call Doreen Jackson at 904-395-1017. In Volusia County, call Kay Haas at 904-723-2058.

Abuse Registry
Trained operators at this toll-free number receive abuse reports and assign them to local investigators. Across the state call 1-800-96-ABUSE.

Thousands lack vital treatment — state permits it

By Craig Dezern
OF THE SENTINEL STAFF

Emily Isenman left the hospital and its legions of doctors and nurses who tended to her failing 81-year-old body.

Despite warnings from the hospital that she needed constant nursing, Isenman's son put her back into a personal care home. There, by law, no one was allowed to give her medical care. No one could even give Isenman her pills.

Within two weeks, she developed gangrene of her right foot. She arrived at the hospital thin and dehydrated, curled up like a helpless baby. Surgeons cut off her leg below the knee.

Two weeks later she was dead.

Isenman's son had approved of his mother's return to the Orange County home in spring 1987. "Who can afford nursing homes at $20,000 a year?" asked Andrew Isenman, who is retired himself. He said his mother's personal doctor had agreed. And the home's operator offered no protest.

Emily Isenman had no business in Forest Haven Retirement Home, according to state law. State inspectors knew that, but they didn't act until Isenman was dead.

It wasn't until after her death that they concluded the operator had broken the law by keeping Isenman there.

About 10 percent of all personal care home residents are so frail or ill that they should be in nursing homes, according to a recent study by the Florida Department of Health and Rehabilitative Services.

That's more than 4,000 frail and elderly people who aren't getting the medical care they need to survive and hundreds of home operators who are violating regulations by not transferring the residents to safer havens.

Inappropriate placement — as HRS calls the situation — is the most serious problem in these homes, advocates for the elderly say.

Yet HRS inspectors are not trained to identify the problem; the agency's top administrators can't agree on solutions; and the law gives no one in HRS authority to move a seriously ill resident to a nursing home or hospital.

Such problems have been cited repeatedly in studies by HRS and the state's Long-Term Care Ombudsman Council since 1980.

At every level, the system is ripe for failure.

Home operators are responsible for deciding who is fit to move into the homes and who must move out if health deteriorates.

But Florida law doesn't require the operators to have any medical training. They need only be at least 18 years old, have a high school diploma and not have criminal records or abuse reports confirmed by HRS.

Administrators have a tool to help them decide who can live in their homes — a physical examination that must be completed 60 days before or 30 days after a resident moves in.

A doctor or registered nurse practitioner must attest that the resident needs neither confinement to bed for more than seven days nor continuous nursing care.

But many homes ignore that requirement.

In Volusia County, for example, more than 40 of the 80 or so homes have violated state regulations in the past four years by taking clients without proper medical forms or by restraining residents in geriatric chairs or hospital beds — a sure sign that residents need nursing home care.

During annual visits inspectors are supposed to check on residents to make sure that they don't need the care only a nursing home can provide.

The licensing inspectors who visit the 210 homes in Central Florida have college degrees in journalism and management, nutrition and home economics, psychology and sociology.

But none has medical schooling.

If inspectors spot residents who should be moved to nursing homes, they are supposed to send reports to a volunteer team of doctors and nurses that can order the residents moved.

That statewide medical review team was abolished last year by the Florida Legislature, which directed HRS to set up similar teams in each of its 11 districts. The statewide team, which had continued to operate, resigned two months ago in protest over HRS's inaction.

HRS hastily created temporary teams, but the permanent teams will not be in place until next year.

Even if the review teams say someone should be moved, there is no one to enforce the decision because HRS has no legal authority to move a mentally competent resident.

So who's finally in charge of moving the thousands of residents too sick for personal care homes?

HRS's licensing office can fine a home — or even deny its license to operate — if the operator allows seriously ill people to live there.

But that office can do no more, licensing director Connie Cheren said.

Nancy Landry, who oversees Adult Protective Services, said her branch of HRS can move people only if they are mentally incompetent.

Maybe John Miller, chief lawyer for HRS, can say who's in charge.

"I don't know," he said.

State pulls punches in handling rip-off accusations

By Sandra Mathers
OF THE SENTINEL STAFF

Ruth Van Winkle feels betrayed.

She can't understand how the operator of an Altamonte Springs personal care home escaped punishment after taking in her aunt and emptying their joint checking account of almost $3,200.

She can't understand why the state agency that regulates these homes didn't punish the operator or help her 85-year-old aunt get their money back.

"I lost total faith in the system," said Van Winkle, of Apopka.

Ernest Hesse still runs the home, though six Central Florida families have accused him of taking a total of $34,000 from their relatives in the past three years. During that time, the state found he violated regulations in connection with all but two of the complaints, which continue today.

But the Florida Department of Health and Rehabilitative Services didn't refer any of the complaints to state prosecutors and never revoked his license, despite a strong recommendation to do so by the agency's area licensing office in Winter Park.

Hesse, owner-operator of The Family Living Center, says he was only trying to help an old woman and did nothing wrong.

When home operators are accused of financially exploiting their residents, HRS investigates the allegations as thoroughly as it does physical abuse.

But a basic problem remains: HRS doesn't use its full power to penalize home operators even when it concludes that they violated the law. The case of Ruth Van Winkle and her aunt, LaVelle Seilkop, is a classic example.

Van Winkle's frustrating encounter with The Family Living Center began in May 1985.

Seilkop, a retired hat and suit designer, had lived with her for two years. But Seilkop's health was deteriorating rapidly.

She had diabetes, arthritis and high blood pressure. Sometimes she wandered the neighborhood while her niece was at work, offering to share her $100,000 estate with people she met.

When a hospital social worker told Van Winkle about a new, well-appointed personal care home, she toured it and liked it. Van Winkle signed a contract and paid Hesse $3,000 up front from a checking account she and Seilkop shared.

Just 10 days later, Van Winkle received a bank statement showing that the $3,200 left in the account was gone. The bank told her Hesse had used a valid power of attorney, which allowed him to withdraw the money.

Van Winkle immediately called HRS for help, but abuse investigators concluded they could do nothing because Seilkop hadn't been declared mentally incompetent and wanted to stay at the home.

HRS inspectors, however, found that Hesse had violated a state regulation by getting power of attorney from Seilkop without insuring any of her money against potential losses. He said he didn't know it was required.

I lost total faith in the system.

— Ruth Van Winkle

Hesse said he could account for "every nickel" of Seilkop's money.

Hesse violated another state regulation that prohibited him from charging Seilkop for special services not outlined in her contract, investigators found. One such charge: $1,000 for the legal process of obtaining power of attorney.

They noted "a strong potential for future financial exploitation of this vulnerable resident." Yet HRS did nothing but tell Hesse not to do it again.

That wasn't good enough for one district HRS administrator.

Paul Snead, who oversees four Central Florida counties for HRS, wrote a letter to Tallahassee licensing officials, demanding that Hesse's license be revoked.

Amy Jones, former director of the statewide licensing office, responded that "sufficient grounds" did not exist.

"We thought there was clear evidence that Hesse should be revoked for taking people's money," said Jo Ann Linch, area licensing supervisor.

She said, however, that no Hesse cases were turned over to prosecutors, because Jones felt they would not stand up in court.

Meanwhile, Van Winkle said, Hesse showed up at her home, demanding her aunt's jewelry.

"He said, 'Are you going to give it to me or do I have to go to court?'" she said. "I told him to go to court."

Hesse and his wife insist the incident never happened.

In desperation, Van Winkle said, she called relatives in Ohio in the summer of 1985. They eventually moved Seilkop to a nursing home in that state, where she died.

At about the same time as the Seilkop case, the family of 90-year-old Eva Sanborn complained that Hesse had borrowed $5,000 from her. HRS found him in violation of a regulation prohibiting home operators from accepting loans from residents.

The agency recommended that his license be revoked, but it didn't happen. Sanborn died penniless in a nursing home two years ago.

4 The Orlando Sentinel, Friday, February 3, 1989

FLORIDA'S FORGOTTEN ELDERLY

Homes make 'Ugly List' but few get shut down

By Sandra Mathers and Craig Dessern
OF THE SENTINEL STAFF

It's called the "Ugly List."

The 63 entries are a rogues' gallery of personal care homes in Florida. So often have the homes violated regulations governing the care of the elderly that the Department of Health and Rehabilitative Services has branded them the worst in the state.

Many have fallen into such disrepair that they are little more than firetraps where roaches breed unchecked and where the elderly are bilked of money, not given emergency medical care and fed nutritionally inadequate meals.

HRS compiled the confidential list 14 months ago as a guide for Connie Cheren, whose office is responsible for licensing and inspecting the state's 1,478 personal care homes.

But since Cheren joined HRS in October 1987, her office has closed only one of the nine Central Florida homes on the list. Another closed voluntarily. HRS has not renewed the licenses of 14 other homes throughout the state, although four are still open pending state hearings.

And a review of state inspection reports by *The Orlando Sentinel* found homes that are as bad or worse than those on the "Ugly List."

What these homes have in common is a history of repeated problems, many of them severe. They show that HRS will renew a license every year for personal care homes that violate the same state regulations time and again.

Here are three examples from Central Florida — one from HRS's "Ugly List" and two identified by the *Sentinel*:

The Willows

Outside, The Willows looks like the church school building it once was. The one-story, block building blends well into the tree-filled Azalea Park neighborhood of Orlando.

Inside, the smell of urine is overpowering. Recently, a dozen residents sat in the recreation room. Only a handful listened to a halted singer belt out old favorites.

Shrunken old men dozed fitfully in large lounge chairs. A small, bent woman in a wheelchair rasped, occasionally drowning out the music. A catheter bag hung from her chair.

When the woman singer asked the folks to sing along, nobody did.

HRS investigators found a different scene one night in May 1986 when they arrived to look into a complaint that the manager was an alcoholic incapable of supervising residents and that one resident was tied to her bed.

When the two investigators knocked on The Willows' front door, no one answered.

Entering through an unlocked door, they searched for 15 minutes before finding the manager of the 34-bed home. She was "slouching and hanging into walls as she walked," the investigators' report stated.

They found a half-empty bottle of Wild Turkey bourbon in her bathroom. The woman needed help finding her glasses and putting on her hearing aid and shoes.

Investigators said the home was "literally crawling with very large cockroaches," but they could not confirm that residents were tied down. They suspected, according to their report, that the manager had removed bed restraints as they talked to the home's owner, Dick Wilson. He had been called to the home by the investigators.

Wilson said recently that the manager was not on duty at the time and disputed HRS's finding of fault in this and other cases. HRS classified the events of that night as neglect and referred the matter to state prosecutors. No charges were filed. The manager was later fired.

The agency did not seek a court order to remove the residents because it could not prove that anyone's life was in immediate danger, said Jo Ann Linch, area HRS licensing supervisor in Winter Park.

Nine days later, police went to the home to investigate an anonymous complaint that a staffer had pushed a resident to the floor. They found no one on duty, even though HRS regulations require that at least one home employee watch over residents at all times.

Though HRS did not confirm whether a resident had been abused, a staffer was fired, according to an agency report.

HRS did not fine The Willows for any of those violations. "We don't recommend a [fine] for a first-time occurrence," Linch said. "We only fine for repeated or uncorrected violations."

There weren't the first problems at the Willows, though. Three months earlier, a resident died because of what HRS said was neglect.

A woman blacked out and hit her head as she fell. She regained consciousness, and no one at the home sought medical care for her. Six hours later she passed out again and was taken to a hospital. She was dead on arrival.

HRS took no action because the autopsy report "did not indicate foul play or reveal information that could be used to press charges against the facility," according to an agency report. The home was not fined, but HRS ordered its staff to put in writing the need to call an ambulance immediately when a resident becomes ill or is hurt.

In April 1987, The Willows did not report a resident missing until four hours after police picked him up on a ramp to the East-West Expressway near the home.

The staffer responsible for supervising the resident was fired, but the home was not fined, because no such violation had occurred before, Linch said.

Two months later, the agency learned that The Willows' operator, Brett Smith, was charging the family of an indigent resident more than the amount of his welfare check. That is a violation of HRS regulations and grounds for revoking a home's license.

But the home's operator argued that he could accept a "donation" from a family.

In July 1987, Linch recommended to HRS officials in Tallahassee that The Willows' license be revoked. Six months later, an agency attorney suggested instead that the home be fined.

It was not. Eventually, The Willows was ordered to refund $300 to the family.

"We got mixed messages here," Linch said. "The attorney said we should [fine the home], but it was a first-time occurrence. If you go ahead and do it, you're not following policy. The policy needs to be updated."

In February 1988, HRS learned that Smith had been convicted of grand theft in Florida and Utah. But it took the agency until April to inform Smith that state law does not allow felons to be operators or owners of personal care homes.

Other employees, however, can have criminal records, and Smith was allowed to continue at The Willows when he told HRS that he would no longer work as the operator.

Smith was fired in September after police accused him of stealing $3,000 from two residents of the home. Two weeks ago, Smith was charged with stealing $2,000 from a third resident.

He is being held in the Orange County Jail without bail and has pleaded not guilty in the cases. A bond reduction hearing is scheduled Wednesday.

From 1985 through 1987, HRS cited The Willows for 71 violations of state regulations. The home was fined $350 in 1986 and $450 in 1987. Last year's fine has not been paid.

The Willows was last inspected in October when 26 violations were found. HRS is scheduled to decide in the next few weeks whether to renew the home's annual license.

Wilson, the owner, said last week that most of the complaints about the home were unfounded. When told that HRS records confirm wrongdoing in each incident, Wilson said, "How come I don't get to read those records?"

He refused to comment further.

The Willows is not on the HRS "Ugly List."

Spring Brook

A 60-bed personal care home that mainly serves indigent residents opened in Kissimmee in March 1985. Two and a half years later, Spring Brook Retirement Center was on the agency's "Ugly List."

When asked about the listing, the owner, Dr. Jesus Cutiller, said: "I don't care what they say. We're taking good care of residents here."

HRS inspectors disagree.

Agency records show that the home has violated more than 100 regulations since it opened. But HRS has renewed Spring Brook's annual license four times.

During an annual inspection in 1985, the state found that Spring Brook had violated 41 regulations, one of the largest totals of any home in Central Florida, according to HRS records.

Conditions at Spring Brook haven't improved much since then, records show. The home has been slow to correct its many violations, routinely missing deadlines and extensions by as much as six months.

Spring Brook's violations have included poor food, fire safety deficiencies and unlicensed staff giving medication to residents.

During a visit two years ago, a member of a citizen watchdog group that inspects personal care homes made this note in his report: "very dirty, hot and smelly [no air conditioner on] and moldy food in the refrigerator."

In 1987, another member of the district Long-Term Care Ombudsman Council found one staffer in charge of 60 residents, few social activities and no daily medication records — all state violations.

HRS fined the home $1,450 for 19 uncorrected violations during inspections in December 1986 and January 1987. But the agency took 19 months to notify Spring Brook of the fines, and the home took three more months to pay the money.

Cutiller, an anesthesiologist at Humana Hospital Kissimmee, disputed HRS's findings that the home has food problems. Not only is the food good, he said, his residents are gaining weight and are in better shape than when they arrived.

Chris Johnson, resident of Ocean View Manor, Daytona Beach, sits in deserted hallway.

"When you charge $500 a month, you can't expect steak on the table," he said.

Cutiller, who charges from $450 to $750 a month, said it's impossible "to come up perfect" on state inspections.

The doctor, however, has run afoul of regulatory agencies before. He operated a boarding home — Kissimmee Victorian Guest House — for two years until it was condemned by the city and closed in May 1988.

Besides renovating the dilapidated rooms without a building permit, Cutiller was cited for violating 29 city building codes, 24 city fire codes and 30 state regulations, inspection officials said.

Cutiller, who charged tenants $70 to $100 a week, called those problems minor and said at the time, "I don't know why they say it is unsafe."

Ocean View Manor

Ocean View Manor in Daytona Beach has all the charm of a fallout shelter. The concrete-block walls are painted institutional shades of brown and beige. The yard is a sandy scrub marred by patches of dying grass.

On a low concrete porch one recent morning, three residents leaned against a metal rail and smoked cigarettes across South Atlantic Avenue, a sliver of the ocean was just visible behind the Treasn Motel.

Inside the 49-year-old building, the scene was equally dismal.

A dozen or so mentally ill residents, some middle-aged, some old, sat silently in plastic chairs that lined the walls of the lobby. They stared at a television set across the room.

An elderly resident, his sunken cheeks covered by gray stubble, sat in the office of Ed Rice, who has been the operator for two years. The resident's shoe was full of blood. The foot was infected, the skin gray. Two weeks earlier, he used a knife to cut out a corn on his toe.

Rice and two women on the staff chided the man, who had to go to the hospital. He should have told someone that he was hurt.

"They just don't tell us," Rice told a reporter. "Now you see what we do here."

What they do at Ocean View Manor is take care of 76 mentally ill people, some of them elderly. But state records dating to 1985 show that the home, owned by Larry McCaskill and his family until last month, kept breaking HRS regulations.

During annual visits, state inspectors never found fewer than 19 violations of state regulations. Last year there were 23. The average number of violations for 34 Volusia County personal care homes is 8.3 a year.

But Ocean View is not on the "Ugly List."

On Oct. 1, 1984, a young woman diagnosed as schizophrenic disappeared from the home. No one on McCaskill's staff notified police or the woman's family.

The woman was gone two weeks before someone from Ocean View filed a missing person's report. The report was filed only after the woman's mother discovered, by chance, that her daughter was missing.

Two months later, McCaskill said, the woman turned up in a New York shelter where she once lived.

In 1988 a former operator of Ocean View said he felt so guilty about conditions that he wrote a letter to a state inspector.

He pointed out that the meals at Ocean View did not meet the state's minimum nutritional standards. Investigators found that McCaskill spent only 30 cents on each meal he served.

HRS learned of other state violations, which investigators later confirmed: a broken fire alarm, which the administrator said had not worked for at least a year; only three staff members on duty at certain times to take care of 80 people; at night, only one staff member who slept at the home.

HRS's solution: It ordered the home owner to write a plan to prevent the problems from recurring.

The situation did not improve much. Last month, licensing supervisors forsook the home to take in new residents because of dangerous violations of state law. Once again, the fire alarm wasn't working. Among other problems was an infestation of roaches and rodents.

"It's never going to be up to the average person will be able to walk into the building and not shudder," McCaskill said. "I feel bad for the people who have to live in these homes. I'd like to make things a lot better."

He sold the home for $1.25 million, and the new owner has started painting Ocean View and putting in new tile. He has added new freezers and an automatic dishwasher for the kitchen. Other major improvements are planned.

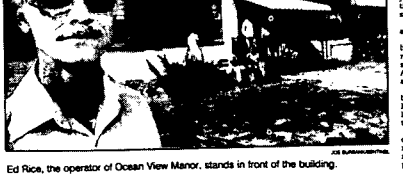
Complaints against homes

Investigated by Long-Term Care Ombudsmen Councils from July 1, 1987, to June 30, 1988:

Top 5 complaints

- Deposits or other money not refunded
- Inappropriately placed residents
- Unappetizing food
- Insufficient amounts of food
- Inadequate or no supervision

Total complaints investigated: 1,488



Ed Rice, the operator of Ocean View Manor, stands in front of the building.

Is food good? 'Like a glob of wallpaper paste'

By Sandra Mathers
OF THE SENTINEL STAFF

Elderly residents of Florida's personal care homes need a healthy diet, but some homes violate state food standards year after year without penalty, inspection reports show.

In Central Florida, 20 homes have had serious nutritional and sanitation problems in the past four years.

Problems ranged from cold, bad-tasting and nutritionally deficient food to rat droppings and food-encrusted kitchen equipment.

Poor food ranks first in Central Florida and second statewide on "problem lists" compiled by the Long-Term Care Ombudsman Council, a volunteer watchdog group that monitors the homes.

Last year district ombudsman councils investigated 284 food complaints from residents of homes throughout the state. Their main concern: not enough to eat and unappetizing food.

The problems at a Daytona Beach home involved more than just bad-tasting meals. After leaving Ocean View Manor as operator in 1986, Kevin Burnor told the Department of Health and Rehabilitative Services about an "atrocious" situation there.

A typical meal for 80 residents, he said, was filled with starch and had little nutritional value. Residents received only three ounces of protein a day and three ounces of milk — if they asked for it. No fresh fruit was served.

HRS inspectors said the home spent less than $1 a day to feed each resident. The statewide average was $3.97 a day, according to a 1985 HRS study.

"It's an attitude of . . . get around what you can," Burnor said.

Nutritional abuses are flagrant. In a lot of the poorer facilities, they try to cut corners. Others don't know what good diets are.

— Joyce Raichelson, Long-Term Care Ombudsman Council

HRS confirmed the problems and required Ocean View to submit a plan to correct them.

Earlier this year, the agency again cited the home for three more food-related problems that took six months to correct.

"I'd have to say some of those things must have been my fault," said former owner Larry McCaskill, who sold Ocean View in November.

Ombudsman council members said food problems are difficult to solve because of infrequent state inspections and regulations that give home operators too much time to correct violations.

Most complaints came from homes such as Ocean View that accept large numbers of indigent residents.

It's a simple matter of dollars and cents — or lack of them.

The state pays homes as much as $308 a month for every indigent resident. But it costs the homes an average of $711 a month to provide adequate care, according to an HRS study.

"Nutritional abuses are flagrant. In a lot of the poorer facilities, they try to cut corners. Others don't know what good diets are," said Joyce Raichelson, coordinator of the ombudsman council.

Hazel Kane, who owns a personal care home in Winter Park and is a member of a district ombudsman council, said food is the only thing many homes can cut to hold down expenses.

In 1984, a resident at Longwood Retirement Village in Seminole County wrote this wry menu review to state licensing officials: "One item they serve here is called chicken and dumplings. . . . If a chicken saw it, it merely flew over."

The casserole, she said, "looked like a glob of wallpaper paste. . . . To a person, all leave the table hungry."

During an investigation last year, an inspector wrote: "Residents said they got a hot meal (during the visit) because an investigator was present and they asked that investigators return frequently."

State inspection reports show that food problems continued at the 180-bed home early this year.

The home's operator, Ellen Weitnauer, said the complaints have stopped since Longwood Village began using a different food distributor that provides more nutritious meals.

"Maybe our food isn't that hot all the time, but you can't satisfy everyone . . .," Weitnauer said. "Some of these people have lost their taste buds; let's face it."

Despite the violations, HRS has never fined Longwood Village for food problems. Rarely has HRS fined any frequent violators.

Jo Ann Linch, an area HRS licensing supervisor in Winter Park, said her office has recommended that agency headquarters in Tallahassee levy fines. But the central office is two years behind in processing the recommendations.

Some home operators complain that HRS's food regulations are hard to follow. For instance, the agency requires them to use an authorized diet manual in preparing meals, but it doesn't provide such a manual.

A new state law requires food handlers, including cooks at personal care homes, to pass a competency test given by the food industry.

The law states that people working at businesses operating before Oct. 1 have until July 1, 1990, to pass the test. Those hired after Oct. 1 must pass within 90 days.

But the test has not been devised.

"We're violating the law now," said Bobby Bickley, an HRS environmental health specialist in Tallahassee. "Those with the 90 days have no test to pass."

State's Scrooge act hurts elderly

Monthly allotment for indigent does not cover the cost of care

By Craig Dezern
OF THE SENTINEL STAFF

The filth of the R&R Guest Home disgusted him, Gov. Bob Martinez said.

On March 10, the governor made a surprise visit to the South Florida personal care home, which housed about 50 residents, almost half of them dependent on a state payment for their care.

Martinez found residents walking barefoot on floors covered with dirt and cigarette butts. He found a 63-year-old man with a scruffy mustache who had lost his left leg to gangrene while staying there.

Standing before a pack of reporters and photographers who had been invited along for the spectacle, Martinez pronounced solemnly, "It's almost sad that under court action prisoners in the state of Florida get better care than senior citizens."

True, advocates for the elderly said, but you get what you pay for.

And, year after year, Florida has paid far less than the actual cost of caring for indigent elderly and mentally ill people in personal care homes, studies by the Department of Health and Rehabilitative Services show. As a result, advocates say, the worst homes are usually those where state clients live.

Florida pays home operators $308 a month for each of the 5,000 or so residents who get state assistance. But a recent HRS study shows that it costs homes an average of $711 a month to care for a resident.

"The rate they are being reimbursed is absolutely criminal. We've set ourselves up to fail," said Kay Haas, coordinator of a district Long-Term Care Ombudsman Council, an advocacy group for the elderly.

Homes that do not accept state clients have an average profit margin of 21 percent, according to an HRS study. But homes that do accept them have an average profit margin of only 7.7 percent.

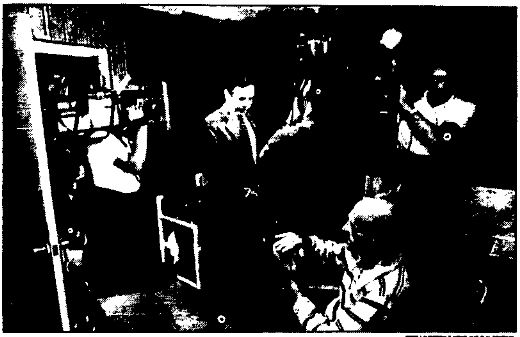
Karen Torgeson, executive director of a trade group, the Florida Association of Homes for the Aging, wrote to Martinez after his highly publicized and — she said — highly political visit to R&R Guest Home in Dania. She was angry that he had compared the treatment of personal care home residents to the treatment of state prisoners.

She was especially angry at the governor's timing. A month earlier he had submitted a budget to the Florida Legislature that failed to include an increase in the state assistance for poor people in personal care homes. Florida pays about $1,050 monthly to take care of each state prisoner, Torgeson pointed out. That's twice as much as the state spends to care for frail elderly and mentally ill people in personal care homes.

"The difference in state commitment to these two programs speaks for itself," she wrote, "and the end results are not necessarily surprising or unexpected."

Although only 11 percent of personal care home residents are state clients, 20 percent of all complaints to the state's chief advocates for the elderly — the Long-Term Care Ombudsman Councils — were made by or on behalf of those residents.

"There are some really lousy personal care homes — mostly where the state clients are," Torgeson said.



FORT LAUDERDALE NEWS AND SUN-SENTINEL

Gov. Bob Martinez inspects the R&R Guest Home in Dania. He said that state prisoners receive better care.

And even when inspectors cite violations at those homes, the owners do little to correct them, said Marie Reyes, coordinator of the ombudsman council that monitors homes in much of Central Florida.

"For a brief period of time, facilities are cleaned up, records are caught up, meals improve and repairs are made," Reyes wrote in her annual report this year. "Shortly after this, an ombudsman will visit and find the conditions as dismal as they were before the 'corrections.'"

A review of inspection records of Central Florida homes by *The Orlando Sentinel* found several that fit the pattern. Ocean View Manor in Daytona Beach and Friendship Village in Titusville are examples. Licensing supervisors placed a moratorium on admissions at Ocean View Manor — a dank and dingy concrete-block structure built before World War II — for a second time in October, when inspectors found dangerous violations of safety standards.

Acting on a tip from Volusia County health inspector Roy Costa, state licensing inspectors visited Ocean View Manor Oct. 11. They found a dozen violations of state regulations, including a broken fire alarm system, inoperable smoke detectors and an infestation of roaches and rodents.

The moratorium was lifted nine days later, after most of the violations had been corrected.

But the problems started at least two years ago at Ocean View Manor, which cares for 74 mentally ill or retarded residents, 51 of them receiving state money. The home has never been cited for fewer than 10 violations during annual licensing inspections, and last year it was cited for 23.

The average number of violations for a Volusia County personal care home is 8.2 a year.

In late 1986, Kevin Burnor, former operator of Ocean View Manor, wrote a six-page letter to licensing inspector June Frye that detailed violations at the home. Burnor stated that he thought the owners at the time, Larry McCaskill and his family, "have allowed the desire to make money to cloud their vision with respect to meeting the basic needs of the residents of Ocean View Manor."

Burnor wrote that the fire alarm system was broken, that no one was watching mentally ill residents at night and that the food was inadequate. A few months after inspectors confirmed Burnor's allegations, licensing supervisors placed a moratorium on admissions when they again found that the home was understaffed, especially on weekends. They also noted that McCaskill, who was then acting as operator, had not been to the home for more than a month.

McCaskill, who sold the home last month to a Canadian businessman for $1.25 million, blames many of his problems on the low state payment. It's nearly impossible, he said, to keep an old building repaired. And the state's regulations cost money. He estimated that it will cost at least $40,000 to add fire protection sprinklers inside.

In Titusville, neighbors said the trouble at Friendship Village started in 1985, as soon as investors converted an unused elementary school into a personal care home for middle-aged people with mental illnesses and old people with Alzheimer's disease.

HRS has found many problems during annual inspections. Last year, for instance, 29 violations were cited, and 14 of them were not corrected when inspectors checked back two months later.

Friendship Village, a collection of three yellow-brick buildings connected by a covered patio, is home to about 60 residents. Fifteen are state clients.

"HRS says we have to do this and this and this," operator Libby Hartman said. "But they're not willing to pay us to do this and this and this."

The district Long-Term Care Ombudsman Council that monitors Brevard County homes recommended that Hartman be required to hire extra staff. But Hartman said it's tough to meet minimum levels at the pay scale she can afford.

The state payment is so low that 63 percent of the homes won't even accept state clients.

An HRS official, however, points to Chipola Retirement Home in the Panhandle as proof that a home can give good care for $308 a month. But the owner, Mary Sittman, said she won't be taking state clients much longer. "We're doing something I never wanted to do when I started in this business, and that's make decisions based on ability to pay," she said. "I almost feel unethical."

Advocates say the solution is simple: Raise the reimbursement rate. A preliminary HRS budget for next year recommends that the state supplement be raised from $308 to $593 each month. That would mean a yearly increase of about $5 million.

Will the governor and Legislature buy it?

"We just aren't interested in paying any more money without knowing what we are getting in return," Martinez said in an interview recently. "It's obvious that there were many providers not delivering the service for what they were being paid."

Will he support the increase?

"You'll have to wait till February on that."

Mattie Bell gazes out the window of her room in the Chipola Retirement Home, which takes many state clients.

Owner Sandra Godzik of the Henry Davis House, considered a top personal care home, dances with 96-year-old Louis Wagner.

1,200 hours of training vs. none

Rules about being beautician stiffer than those for care givers

By Sandra Mathers

OF THE SENTINEL STAFF

Kim Kinney cuts and styles hair in Orlando. She charges $25 a person for a haircut and about $45 for a perm.

To get a state license, she had to complete 1,200 hours of cosmetology training — equal to five months of schooling — and pass a written test.

The 1,500 people who operate personal care homes in Florida charge about $800 a person each month to care for old people who can't care for themselves.

To get a state license from the Department of Health and Rehabilitative Services, they didn't have to pass a test or have any training. They only had to be 18 years old, have high school educations and not have criminal records or abuse reports confirmed by HRS.

Advocates for the elderly say the training requirements are too lenient, considering the many responsibilities that go with running a personal care home. Within a year of receiving their licenses the operators are required to take 15 hours of classes to retain their licenses.

Operators must offer nutritional meals and keep 36 different kinds of records. The operators must recognize often subtle physical changes in residents that are signs that they should be moved to a nursing home or hospital.

Last year the state Long-Term Care Ombudsman Council, a volunteer watchdog group, criticized HRS for what it called inadequate and inconsistent training of the people who inspect the homes.

The council's 1987 annual report recommended that HRS "increase the credibility" of the licensing office by providing additional and "meaningful" training to its staff.

The 15 hours of training that HRS gives home operators cover general information about nutrition, mental health, medications, contracts, home management, hiring and other topics.

HRS also requires some employees of homes to be trained in first aid, personal hygiene and food service management.

In the Orlando area, however, some of the training is not available, hard to get or costly for employees who are paid little more than the minimum wage. Personal hygiene has not been taught for months, said Jo Ann Linch, area HRS licensing supervisor in Winter Park.

The Visiting Nurses Association, which had been offering a combined first aid and hygiene class in Central Florida for $25, discontinued it early this year when the trainer left town, Linch said. Only the American Red Cross in Orlando offers an HRS-approved first aid course, which costs $20.

"Very few [operators] hire trained staff," she said. "We send in many [fines] because people haven't gotten the training."

Margaret Jacks of Tallahassee, who helped write the licensing law for personal care homes, said there isn't enough training and that what there is isn't very good.

"It's superficial. You can't meet for one and a half days and change people" said Jacks, who is former head of the ombudsman council and a former HRS official.

Candy Rechtschaffer, a former HRS employee who helped implement the licensing law, agrees. She calls the agency's training "useless."

"You've got the mom and pop type of person all the way to the person who has a master's degree," said Rechtschaffer, who operates a personal care home in Hollywood. "That person sits there totally bored, and the mom and pop sit there saying, 'What are they talking about?' "

HRS has no standardized training program for inspectors or a written policy manual for them to follow when visiting a home.

The agency's Office of Licensure and Certification in Tallahassee "doesn't train people properly to go into these places," said Virgie Cone of Jasper, outgoing head of the ombudsman council. "We'd ask OLC what training they gave staff, and they weren't able to tell me. They told me they don't have enough staff to do training."

Barbara Hallihan, head of the area licensing office in Jacksonville, said: "There is no set time or way to go about it [training]. We need a brief, concise, well-written policy manual."

The director of HRS's Office of Licensure and Certification, Connie Cheren, said improvements are on the way. The agency is writing its first policy manual for inspectors.

Last month Cheren hired someone who will specialize in training inspectors throughout the state.

Care seekers must do their homework

Check for license and ask a lot of questions, the experts advise

By Craig Dezern

OF THE SENTINEL STAFF

Peek into the doorway of Henry Davis House.

Notice the country charm of the weathered upright piano, the chintz-covered couch, the hardwood floors and the big oval table where fresh eggs from a backyard henhouse are served in the morning.

That's what Sandra Godzik hopes visitors will see when they step into the two-story, clapboard farmhouse.

"I just want them to stand a while and sort of absorb the aura of the place," Godzik says.

Then she wishes they'd ask her some questions, like: Where is her state license? What services do Godzik and her husband, Frank, offer? What kind of food do they serve, and what qualifies them to take care of the frail, elderly men who live there?

Godzik knows she runs a good home, one of the best in the area, experts say. But few people who visit the 82-year-old house in north Orange County even know what a personal care home is. Even fewer are prepared to ask questions.

Such ignorance can be dangerous.

Shirley Zuclich of Melbourne remembers the day she took her 81-year-old father, Max Darevsky, to the Merritt Island home of a woman who introduced herself as Dottie White.

"The home was beautiful," Zuclich said. "She showed me the chair where he would sit."

Zuclich, 59, had found the home through a classified advertisement. She didn't know that she should ask to see a state license. She didn't think it was strange when White told her she could visit her father only on Sundays.

Within two months her father was in a coma and covered with bedsores. He was removed from the home and died a month later of a heart attack. White, whose real name is Lori Engelleiter, was convicted of abusing Darevsky and sentenced to five years in state prison.

"I learned so much, too late for my dad," Zuclich said recently.

"Check for the license," she warns others. "See if they're accredited, if there have been any charges levied against them by the state. Get the references. Check them out."

That's good advice, the experts say. Most of the 210 personal care homes in Central Florida offer adequate care, but you can't be too careful.

First, you must decide the level of care that is needed. Remember, these homes are not nursing homes. Residents of personal care homes cannot be bedridden, and they must be able to take their own medicine.

The quest for good personal care should begin with a list of homes that have state licenses. A home must have a license if it provides services such as bathing, grooming and feeding for more than three people or advertises that it will provide those services.

Nursing homes are rated by state inspectors. Personal care homes are inspected but not rated.

To check on a specific home, call the office of the Long-Term Care Ombudsman Council in your area. Those advocates for the elderly visit every home every year. They also receive complaints about homes.

Donna Jackson, coordinator of the council that works in Lake County, said she will warn consumers about bad homes.

"HRS can't tell you, because of confidentiality," Jackson said, "but you call me, and I'll tell you there are problems. I'll say, 'We've had a lot of complaints on that home.' That turns them off right away."

Next, call to arrange a visit to the home. Try to arrive during a meal so you can see if residents are being served nourishing food.

Tour the home. Talk to residents. Do they seem happy? How do they spend their time? Ask to see a copy of the home's activity calendar.

Introduce yourself to the staff members. How have they been trained? Is there someone on duty at all times who is certified in first aid?

Ask to see the home's license and the results of the last inspection by the state's licensing office. Every home should have both those items prominently displayed, along with a copy of the "Residents' Bill of Rights," which explains how they can report problems to the ombudsman councils.

Ask the operator for a copy of a contract to take with you. Read it carefully, as you would any lease. Are there extra charges for services such as haircuts or transportation to the doctor's office? Will the home refund a resident's money if he suddenly becomes too ill for the home?

Once you find a home you like, visit again. But this time don't let the staff know that you're coming. Is the home as clean this time? Is the meal as good as during your first visit, and does it follow the weekly menu that should be posted?

As a final step, you might consider looking up the home's record in the files at HRS's Licensure and Certification Offices. The office in Winter Park maintains the records for Orange, Seminole, Brevard and Osceola counties. The office in Jacksonville handles Lake and Volusia counties.

Those files, which are open to the public, should contain annual inspection reports, complaint reports and applications for licensing.

Personnel regulations have loopholes, are almost impossible to break

By Sandra Mathers

OF THE SENTINEL STAFF

The neighbors were appalled.

Former mental patients were wandering the streets, climbing into windows and urinating in front yards.

The reason: Friendship Village, an 80-bed personal care home for the mentally ill and elderly, did not employ enough staff to monitor hard-to-control residents who behaved bizarrely.

Neighbors decided to take action. They called their county commissioner. They met with zoning officials. And they contacted the state agency that licenses and regulates these homes.

Nothing worked.

"I can understand the need for the home, but you can't just let them roam the neighborhood," said Lilly Jeffcoat, who lives next to Friendship Village in Titusville. "Some of the men would just urinate in the streets."

The state's staffing requirements at personal care homes such as Friendship Village are almost impossible to violate. They allow one person to care for an unlimited number of residents. The staffer can be any employee, even the night watchman or the cook. Some homes pay a resident to supervise the other residents.

The Department of Health and Rehabilitative Services has the power to order a home to increase staff but rarely uses it. As a result, the staffing problems that surfaced at Friendship Village in April 1986 continued until the fall of 1987. A group of advocates for the elderly, not HRS, asked the home's owners to improve supervision.

Friendship Village eventually solved the problem by accepting only residents who require less supervision.

Today HRS's staffing requirements remain unchanged despite the pleas of agency officials who license the homes and of advocates for the elderly.

So problems such as those that plagued Friendship Village continue unchecked in many personal care homes throughout Florida. Small staffs and constant turnover are partly to blame for residents getting poor care.

"The staffing regulations are really horrendous," said Joyce Raichelson, director of Florida's Long-Term Care Ombudsman Council in Tallahassee. "There is nothing that says when those [staff] people have to work. . . . Even a resident can be in charge."

HRS's staffing regulation is vague and full of loopholes:

■ Staff-to-resident ratios are based on a 24-hour period, not specific work shifts. For instance, three full-time staffers are required to care for 16 people but can work three different eight-hour shifts, leaving only one employee on duty.

■ Because the regulation does not define staffers' duties, such as personal care aide, cook or maintenance worker, any one of those employees can perform all of those jobs at one time — and be the only person on duty.

"That's why a big retirement center can hire a night watchman [as the sole staff] at night and be covered," said Jo Ann Linch, area HRS licensing supervisor in Winter Park.

■ The regulation defines full-time staff as those working a 40-hour or five-day week. On two days of each week, homes can have only one person on duty for 24 hours straight.

HRS has been aware of the staffing problem for years. A legislative committee report pointed it out eight years ago. And the agency itself found similar shortcomings in a 1983 study.

The study, noting that in one home a staffer was caring for 40 residents, recommended that staffing requirements be improved.

The state Long-Term Care Ombudsman Council, a watchdog group that monitors the homes, has urged HRS to improve staffing. Last year, and again this year, the council asked HRS to set staffing standards by shifts, rather than a 24-hour day.

And every time Linch's bosses in Tallahassee ask for suggestions to improve regulations at personal care homes, she points to staffing.

"These operators know only one person can care for any number of people, and they use that," she said.

Margaret Lynn Dugger, assistant secretary of HRS's Aging and Adult Services, said the agency is aware of the problems with staffing and would like to improve the situation.

So why has HRS done nothing? Dugger's lieutenant, Nancy Landry, gave two reasons: The cost of adding more staff would force the homes to raise their rates above what many residents could afford; also, the agency already has the power to order homes to increase staff.

However, HRS rarely orders homes to hire extra staffers. Two supervisors who regulate personal care homes in 60 of Florida's 67 counties said they have taken that action only a handful of times.

Ordering extra staffing "places the burden on us," said Barbara Hallihan, a supervisor in Jacksonville who oversees 41 counties. "We couldn't tell someone they need more staff and make it permanent. We're not set up for that type of monitoring."

Convictions don't keep workers from coming back

By Craig Dezern
OF THE SENTINEL STAFF

On a summer day four years ago, Max Derevsky walked into the Merritt Island personal care home run by Lori Engelleiter. Less than two months later, his daughter carried him out in a coma.

Bedsores left blackened splotches of dead skin — some more than six inches across — on the 81-year-old man's back, buttocks, scrotum, ankles and feet.

Derevsky had been left sitting in his own excrement for days. He never fully recovered from the abuse, doctors said, and died of a heart attack in October 1984, six weeks after he left the home.

"No human being should die the way my father died," Shirley Zuelsch said recently.

Brevard County jurors felt the same way in October 1985 when they convicted Engelleiter of abuse. She spent about two years in prison.

Now, one year after her release, state investigators believe that Engelleiter may be again working with old people at a personal care home. This one is operated without a license by her son, William, in Satellite Beach.

When investigators found Engelleiter at the home, she denied working there, then asked one question: Would it be legal for her to take care of old people again?

Yes.

Engelleiter

There is no law to prevent a convicted abuser from working with old people in a personal care home.

Since 1985, HRS has tried to prevent child abuse by screening every worker in state-licensed centers. Using fingerprints and elaborate background checks, the agency has identified hundreds of child-care workers who have criminal convictions. As a result, the workers either quit their jobs or were fired.

But there is no law to prevent a convicted abuser from taking care of the elderly. No one checks the criminal histories of the people who work in Florida's 1,479 personal care homes. The law requires only that the operators and owners of these homes have no felony convictions and no abuse reports confirmed by HRS.

Earlier this year, a background check on Brett Smith, the operator of an Orlando personal care home, found that in 1986 he had been convicted in Utah and Florida of forgery and grand theft.

Slipping through that loophole, Smith declared that he was no longer the operator of the home, called The Willows. Instead, he said, he was merely an employee.

Smith is now charged with stealing $3,000 from residents. He has pleaded not guilty.

Why do children receive protection from abusers but the frail elderly don't?

"I think we have a very 'age-ist' attitude in this country," said Connie Cheren, director of licensing for the Florida Department of Health and Rehabilitative Services.

"If you're 6 years old and you need occupational therapy, you're going to get it. If you're 80 and you need occupational therapy, I'm not so sure you're going to get it," she said.

Cheren said her agency has no plans to ask the Florida Legislature to expand the criminal background check program into personal care homes.

Making the checks would be too expensive, Cheren said, and she is not convinced that they would do much good. "Can you really safeguard by doing those kinds of checks?" she asked.

So no one can stop a convicted abuser from working in a personal care home.

David Silverman is troubled to hear that Engelleiter may be caring for the elderly again. He thought he had finished her career in 1985 when he prosecuted the case as an assistant state attorney.

"The victim's family had made repeated complaints to HRS to no avail," said Silverman, now in private practice in Melbourne. "She resisted all efforts by anyone to stop her."

At Engelleiter's sentencing, Brevard County Circuit Judge John Antoon II noted her long and varied criminal history: Since 1983 she had operated five unlicensed personal care homes, and six abuse complaints had been filed against her. She had 25 previous convictions, 29 aliases and six Social Security numbers. She listed seven dates of birth.

Antoon sentenced Engelleiter to the maximum penalty of five years in state prison. She was released almost two years later.

Shirley Zuelsch, 60, still is serving her own life sentence of guilt.

She has a grocery bag full of court documents and an envelope of photographs that she can't force herself to look at.

The pictures were taken at the hospital by investigators, and they show her father's naked body, section by section. Low on his back and buttocks is a purplish black bedsore eight inches across. In the center of his back is a watery red smear where another sore festers. Smaller sores mark his heel and legs. One sore has eaten through his blackened scrotum until his testicles protrude.

"I learned so much, too late for my dad," Zuelsch said. "My father walked in there. We carried him out."

"There's not a day goes by," she said, "that I don't think of my father."

License checkers bark but they seldom bite

By Craig Dezern
OF THE SENTINEL STAFF

Ruth Robertson's two-story stucco house is solid and settled. With its thick walls and heavy wooden door, it looks like a fortress.

Entrenched in that stronghold — painted lipstick pink like the beauty shop she owned in her Kansas hometown — Robertson has foiled investigators from Florida's Department of Health and Rehabilitative Services.

Since 1981 the agency has failed to stop her from running an unlicensed personal care home in Orlando, where she takes in frail and failing old women who need help eating, walking, taking medicine and using the bathroom.

Robertson's neglect contributed to the death of one of those women in 1986, HRS investigators wrote in a report. But she never was charged with a crime after 83-year-old Margaret Hamilton wasted away, and Robertson never was stopped from operating the unlicensed home.

In the shadows of Florida's personal care home industry, hundreds of people like Robertson operate unlicensed businesses in flagrant and fearless violation of state law. No state agency is responsible for finding the illegal homes, so most are never found.

Robertson, for instance, ran her home for eight years before state investigators discovered her. She continued to operate illegally even after Hamilton's death and after findings by HRS that she neglected other residents.

> We do not have the manpower to go out looking for them. But we do follow up leads when they're given to us.
>
> — Jo Ann Linch

The Robertson case points out the state's twin failings in dealing with unlicensed homes. It can't find them; it can't shut them down.

Simply operating a personal care home without the required state license is a felony that can bring a prison term of five years and a fine of $5,000 on conviction. But that hasn't happened in Central Florida, even to people like Ruth Robertson:

- Robertson started taking care of people in her home in 1973, but investigators first found out about the unlicensed operation in 1981, when they checked out a complaint of abuse there. They removed a mentally retarded man but did not prove abuse.
- In February 1986, investigators ruled that Robertson's neglect contributed to the death of Hamilton, who, emaciated and dehydrated, was taken to an Orlando hospital and died within a day.
- Four months later, investigators decided that Robertson had neglected the three elderly or disabled residents in her home by locking them inside for hours while she went shopping.
- She still had no license when a reporter recently found three old women and the same mentally retarded man living in her big pink house at 822 Menendez Court, near Humana Hospital Lucerne.

Robertson — a short, stout woman who says she's 54 although her driver's license states that she's 58 — disagrees with the state's findings. And she doesn't care much for the state investigators and their threats of action that never comes.

"They've tormented the hell out of me," she said.

But in eight years, they've never shut her down.

Since 1986, running an unlicensed home has been a third-degree felony. Yet state inspectors rarely turn over the cases to state attorneys' offices, and no case has been prosecuted in Central Florida, licensing officials said.

Jo Ann Linch is in charge of licensing personal care homes in much of Central Florida. Since June 1987, she said, she has referred five unlicensed homes to the state attorneys in her area. Only once has a state attorney pursued a case, and charges were not filed against the operator, Linch said.

"It isn't anything the state attorney is going to lose sleep over," said Connie Cheren, state director of licensing. "They don't even want to prosecute when there's abuse — confirmed abuse — let alone when you've just got somebody keeping four people and bathing, dressing and feeding them and not being licensed."

David Locker, who investigates most of the complaints against personal care homes for the Orange-Osceola County state attorney's office, could offer no explanation.

"There really isn't any reason that comes to my mind as to why we don't work these cases when they come to us," he said. "These are pretty easy [to prosecute]. If they're not licensed, they're not licensed."

Tim Hetz, a spokesman for the state attorney's office, said, "We simply have not focused on old people, and we need to, because we're all going to be old some day. We need to get some commitment from prosecutors and investigators to go after these cases."

By law, everyone who provides housing, food and personal services for more than 24 hours to more than three unrelated people must have a license from HRS. Also, anyone who advertises such services, even by word of mouth, must have a license and be inspected every year.

How many people are breaking the law?

There's no firm estimate, because no one is looking for them.

"We do not have the manpower to go out looking for them," Linch said. "But we do follow up leads when they're given to us."

When inspectors find an illegal home, as they have done in Central Florida only 29 times since 1984, there's no dramatic arrest of the operator, no flurry of social workers moving elderly residents to safe havens.

Instead, a bureaucrat has 30 days to send a form letter that says the operator is breaking the law and must apply for a license within 10 days. But the licensing office allows 15 days for a reply, Linch said.

A determined operator can stay in business for years, interrupted only occasionally by the loud, but toothless, barking of inspectors.

Ginny Prevatt of Orlando ran an unlicensed home for 12 years before a state investigator showed up at her front door one summer day in 1986.

"It made me mad," Prevatt, 50, said. "I told him, 'Hey, I'm not here to hurt these people. I take care of these people like I'd take care of my own mother and dad.'"

She finally complied but only because she felt like it, Prevatt said. She no longer advertises and cares for no more than three residents at a time.

"But if I decide to take five," Prevatt said, "I will, because they aren't going to come out here and check."

Like Prevatt, other operators view HRS as a nuisance, not a threat. Some of the agency's Central Florida records explain why:

- HRS took 19 months to issue a license to a Eustis woman who was found operating an illegal home. Between December 1985 and July 1987, HRS allowed Barbara Corron to continue caring for three elderly women and even bring two more into the home. But the agency never inspected the home during that time because it had no license.

"I really didn't want to bother with HRS, because their nit-picking rules have nothing to do with caring for the ladies," she said.

- In 1983 and 1984, HRS investigators twice dropped their inquiries into complaints that a home was operating illegally. Their reason: The owner wouldn't let them inside. State law lets the agency seek a court order allowing inspectors to enter any home they suspect has no license, but no order was sought.

A New Smyrna Beach woman simply said no in April 1985 when HRS employees asked if they could look inside her house to check out a report that she was running an unlicensed home.

An HRS inspector investigated another complaint in June 1986. Again, the woman denied that the house was being used as a personal care home. Again, she refused to let him inside.

Without seeking a court order, HRS recommended that the complaint be closed because it couldn't be confirmed or denied.

* * *

Ruth Robertson's pink stucco home could be a shrine to the state's impotence in dealing with unlicensed homes.

The trouble started Feb. 24, 1986. At 4 a.m. that day, Margaret Hamilton was taken to a hospital from Robertson's home.

The 83-year-old great-grandmother was in a coma. She weighed only 70 pounds, 30 pounds less than she had weighed three months before. She was emaciated and dehydrated. Her body temperature was 94 degrees. She had many bedsores and blood poisoning.

Dr. Sue Freyhofer was "appalled at the condition of the patient," the HRS report stated. The doctor "definitely thought her condition was due to neglect."

The report concluded that Robertson's neglect of Hamilton contributed to her death and recommended that licensing supervisors "take whatever steps are necessary to prohibit Mrs. Robertson from operating a care facility."

After Hamilton died, HRS officials removed a mentally retarded man from Robertson's care and gave the case to the Orange-Osceola County state attorney's office.

"Apparently there wasn't anything done on it," Locker said. "It may have fallen through the cracks."

Robertson is still upset and bewildered that the state would accuse her of neglecting Hamilton.

"I don't know how they figured that. She was old; she died," Robertson said recently. "Old people get skinny. I wasn't expecting her to sink that fast.

"There isn't any law against dying," she said.

On June 5, 1986, abuse investigators received an anonymous complaint against Robertson.

She had three residents, two old women and the same mentally retarded man who had been removed from the home four months earlier. She locked them in the home for hours at a time while she went shopping, according to the complaint.

When investigators questioned Robertson, she said the women were her aunts and that she had two more "aunts" coming to live with her soon.

Robertson denied leaving them unsupervised. A neighbor came over to watch them, she said.

The neighbor denied that.

When confronted, Robertson admitted that she locked the residents in the house while she went shopping, investigators said.

"You'd lie, too, if your livelihood was threatened," she told investigators.

Their report concludes, "The incident occurred because Ruth Robertson has chosen to violate state statutes which require licensing."

The women were sent to licensed personal care homes. A report was sent to the state attorney. A letter was sent to Robertson, telling her she had 10 days to apply for a state license.

Once again, no charges were filed. Robertson never applied for a license.

During a recent visit by a reporter, she was taking care of three frail women, ages 76 to 95, and the same mentally retarded man.

Inside her pink stucco fortress, Ruth Robertson was still in business.

Ruth Robertson's unlicensed personal care home at 822 Menendez Court, Orlando.

Most Floridians have no right to know where abuse occurs

By Sandra Mathers
OF THE SENTINEL STAFF

At least 35 people have been abused in personal care homes in four Central Florida counties during the past two years. But the state will not disclose the names of those homes.

Florida law prohibits the Department of Health and Rehabilitative Services from releasing to the public any information about abuse that its investigators have confirmed in Orange, Seminole, Osceola and Brevard — or any other county.

The Adult Protective Services Act allows HRS to give its findings only to a handful of people: the victims, their guardians, the abusers and attorneys involved in the cases.

The law, however, wasn't intended to foil consumers who want to know whether a specific home is safe, said Jim Sawyer, an HRS attorney in Orlando. It was written to protect victims from embarrassment and their abusers from being stigmatized.

Sawyer said he has "some problems" with the law protecting the identities of abusers. He said they may have been shielded because of "sloppy drafting, or it may have been lobbied for by industries that care for adults."

But others in the agency said there is a reason for protecting the identities of employees of personal care homes who have abused residents: the findings of an HRS investigation, unlike a jury's verdict, does not prove guilt beyond a reasonable doubt.

HRS investigators can only confirm for agency officials whether someone has been abused and who inflicted the abuse. But "a perpetrator is not guilty under our findings," said Chris Shoemaker, administrator of HRS' Adult Protective Services System.

Employees of personal care homes can appeal an HRS finding that they committed abuse, a process the agency calls "expunction."

If an appeal is successful, HRS must erase an employee's name from a computer bank. That is important to owners and operators of personal care homes, because they can't be licensed if HRS has confirmed they were involved in abuse of a resident.

When HRS concludes that someone has committed abuse, the agency allows the person 30 days to appeal and to provide more information that could help his or her case.

If the facts clearly show abuse occurred, the appeal is denied, said David DuBois, an HRS personal care home consultant in Tallahassee.

In cases that aren't clear-cut, HRS licensing officials in Tallahassee make an informal decision on whether or not to wipe out the record. This process is not guided by any written policy.

"These are generally common sense decisions," DuBois said.

He did not know how many "expunctions" his office has granted because no records are kept.

But someone accused of abuse by HRS who loses an appeal to the agency has yet another recourse — a state administrative hearing.

Of the 40 adult abuse hearings held by the Department of Administration during the first nine months of this year, more than half the cases — 22 — were overturned, according to an HRS spokesman.

"When we present information [at a hearing], we are not required to prove beyond a reasonable doubt, but the hearing officer is using that or similar criteria" to decide the case, he said.

The high percentage of cases overturned by hearing officers concerns HRS. The agency's legal office in Tallahassee is studying the appeals process and will make recommendations to HRS Secretary Gregory Coler, Shoemaker said.

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FLORIDA'S FORGOTTEN ELDERLY

Deadly situation: HRS units don't communicate

By Sandra Mathers
and Craig Dezern

OF THE SENTINEL STAFF

When one branch of Florida's giant social service agency doesn't talk to another branch, people can die.

In July 1985, Jay Clark died after an eight-month stay at Green Acres Retirement Home, which was inspected and licensed by the state's Department of Health and Rehabilitative Services.

The 84-year-old woman was malnourished, dehydrated and covered with bedsores when she was transferred from the Orlando personal care home to a hospital.

Abuse investigators from HRS' Aging and Adult Services in Orlando determined that Clark died of neglect, but they never passed on that finding to the agency's area licensing office in Winter Park. Instead, they informed the state licensing office in Tallahassee — and that office never shared the information with its Winter Park office.

If she had been told about the findings of neglect, said Jo Ann Linch, supervisor of the area licensing office, she would have tried to close down Green Acres.

But no one told her until two years later — when Lola Barnhardt died at Green Acres.

Like Clark, Barnhardt, 82, was malnourished, ill and covered with bedsores. And like Clark, she died because she had been neglected, abuse investigators said.

When the operators of the home were arrested in March, they said they had done nothing wrong. Opal Terrel and her son Bryan pleaded not guilty after criminal charges of neglect were filed. Their trial is scheduled for April.

In a recent interview, HRS Secretary Gregory Coler credited The Orlando Sentinel's coverage of the deaths with pointing out "a very important weakness in the way the department was doing business."

"There was no communication" between abuse investigators and licensing officers, Coler said. Now, he said, "As standard practice, abuse reports ... will be reviewed as part of the licensing review."

The Green Acres case is just one symptom of the perpetual problems confronting HRS as it tries to take care of millions of Floridians from cradle to grave. Among its myriad responsibilities are overseeing adoptions, day care centers, county health departments, food stamps and Medicaid.

The agency's Office of Licensure and Certification alone monitors 28 programs, including abortion clinics, birthing centers, nursing homes, hospices, rural health clinics, hospitals and personal care homes.

JOE BURBANK/SENTINEL

Gregory Coler: Size is HRS weakness. Connie Cheren: Abuse inspectors need time.

"HRS is not a mom and pop store," Coler said. "We are the biggest (state) health and social welfare agency in the country. We have more employees than Eastern Airlines — 40,000 plus. A $4.7 billion budget. We'd be the 100th largest company in the Fortune 500."

Coler explained why that bigness can confound HRS.

"HRS's strength is its weakness — its size," he said. "What's the most difficult thing about size?

"Communication."

Like a dinosaur, HRS is so big that by the time its brain can tell its legs to stop running, it's already over the cliff.

To understand, here's a quick lesson in HRS-speak.

The agency has two branches that deal most often with personal care homes and the 44,000 elderly and mentally ill people who live in them — the Office of Licensure and Certification and the Office of Aging and Adult Services.

The licensing office inspects each home annually and investigates complaints of safety and health hazards. The central licensing office in Tallahassee divides the state into four areas, each with its own office and staff.

Aging and Adult Services investigates complaints of abuse, neglect or financial exploitation of residents. HRS in Tallahassee divides the state into 11 service districts, each with its own aging office and staff.

The two offices often must work together, but their paths do not cross until they reach the office of Deputy Secretary Bob Williams, who supervises all HRS programs.

The two branches often do not talk — to each other or to the home operators — even when ordered to do so by the head of the agency:

■ Despite the order from Coler, investigators for Aging and Adult Services still are not sharing critical abuse findings with licensing inspectors in Orange, Seminole, Osceola and Brevard counties.

Even after the second death at Green Acres, Linch said, abuse investigators don't send reports to her Winter Park licensing office, which covers those four counties and 15 others. Linch said she discovered the flaw still exists several months ago when she learned of a case from another source.

Connie Cheren, director of the state licensing office, said it will take time for abuse investigators to feel comfortable sharing reports that by law must be kept from the public.

"You've got Aging and Adult Services who for years have held those reports confidentially. It's their bible. It's what they've been raised to believe. Now, you're saying you have to share those reports with (the licensing office)."

Paul Snead, who oversees Aging and Adult Services in the Orlando district, denies that there's a communication problem and said his abuse investigators are following proper procedures for notifying the licensing office.

But Marie Reyes, coordinator of the Long-Term Care Ombudsman Council, a volunteer watchdog group in Snead's district, said that the communication gap still exists and is endangering residents of personal care homes.

"The cases I'm concerned about are the emergency situations where a place needs to be closed," Reyes said. Aging and Adult Services can remove residents, "but they can't close a home."

■ As the Green Acres case shows, the licensing bosses in Tallahassee often don't communicate with their employees in the four area licensing offices.

For instance, the law governing personal care homes was changed significantly in October 1987 and took effect last June. But the central office failed to send copies of it to area offices until late August.

For more than a month, area licensing inspectors were supposed to be enforcing a law that they hadn't even seen.

Operators of personal care homes know that inspectors get little support from their supervisors in Tallahassee, say members of the state ombudsman council. In the group's 1987 annual report, council members wrote:

"Time and time again, (inspectors') decisions are overturned by superiors who 'cave in' to operators who threaten to cause trouble .... After this happens a number of times, the regulatory agency becomes the laughingstock of the industry."

But that's changing, Cheren said. "I'm beginning to hear now that...operators are beginning to sit up and take notice" when licensing inspectors go in.

"And that's sure different," she said.

■ The Tallahassee licensing office also waited until last month to notify the home operators of changes in the law — more than a year after it was changed. For months, the operators were supposed to comply with a law they had never seen — a law that makes it easier for HRS to close bad homes.

"It's a courtesy for the state to send those out to them," said Cheren. The home operators, she said, are responsible for knowing the laws.

Her boss disagrees.

"It certainly makes sense to me" to send the law to the homes, said Coler.

■ The state licensing office has sent two memos that baffled county health departments, which once visited personal care homes at least once a year.

In late 1983, the state director of licensing informed county health departments, which also fall under HRS supervision, that licensing inspectors would take over the inspection of homes.

In early 1984, the licensing director wrote a second memo to clarify the first. He never meant to imply, he said, that health department inspectors couldn't visit personal care homes. In fact, several Florida statutes require health departments to inspect these homes.

But the seeds of confusion already were sown.

In Central Florida today, only Seminole and Volusia county health departments regularly send inspectors into personal care homes. The others now believe their only responsibility is to respond to complaints.

■ Compounding the communications gap between abuse investigators and licensing officials was the demise of HRS's only interagency committee that brought together representatives from every program that deals with the elderly in Central Florida.

Its job was to ensure that abuse and other serious incidents at personal care homes were investigated properly.

But Snead disbanded the Long-Term Care Coordinating Committee in February because of "a staffing problem." He said his secretary, who had been serving as committee coordinator, no longer had time to do the job.

■ Even at the top of the agency, there are gaps in communication. Cheren and Coler contradict each other on at least two major issues.

Last year, the Legislature rejected HRS's request for 43 new nursing positions. The agency plans to ask again in the spring.

Cheren says adamantly that the nurses would not be visiting personal care homes to see whether residents are so sick that they need to be moved to nursing homes or hospitals. Personal care homes, she said, are not supposed to provide nursing services.

But Coler said: "That's exactly what we do need some nurses for. We need some medical people going into the (homes)."

On the subject of fines, they are just as far apart.

From June 1986 to April 1988, the state licensing office levied 241 fines totalling $155,800. But it collected only $41,900.

Since 1985, the licensing office has fined Central Florida homes 67 times. But the office has collected in full only 21 of the fines, also called sanctions. More than $20,000 in fines — some as old as three years — has not been paid.

"That has a low priority," Cheren said. "Fining just gets set aside."

Said Coler: "I think it's very important we get on top of this sanctions thing."

The state licensing office has proposed a reform plan that it hopes will fix two major communication problems.

Coler developed the plan with Cheren, who took over the licensing office a year ago. In that time, Coler said, Cheren has made significant progress.

She has issued 40 orders that prohibit homes from taking new residents until their problems have been corrected. In years past, only a handful had been issued. She has refused to renew the licenses of 54 troublesome homes in 1988. That's more refusals than in the three previous years combined.

But the key to improving HRS, Coler and Cheren said, is the reform plan, which the state Cabinet approved last month.

Under the plan, the four area licensing offices would be expanded to 11 — the same number of offices as Aging and Adult Services and in the same locations. Also, the licensing office, the last major HRS division without computers, will be automated.

If the number of licensing offices is increased, inspectors finally will be covering the same area and the same homes as their abuse investigator counterparts from Aging and Adult Services, Cheren said.

Communication between the state licensing office and the area offices is hindered because the annual inspections are not computerized. Instead of nearly instant on-line access, area offices must communicate by forms that must be sent from one office to another.

The reform plan would change that, Coler said, with a centralized computer system and portable computers for the inspectors.

Coler is pinning his hopes on the computer system to solve many of the communication problems that endanger the safety of personal care home residents.

Without computers, he said, there is nothing to prevent a communication breakdown like the one that allowed a second woman to die at Green Acres.

"If we can get the money for automation that would be a major step," Coler said. "As long as it is the way it is we're going to have glitches."

About the reporters

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Sandra Mathers, 45, has worked at *The Orlando Sentinel* for 17 years. A graduate of the University of Missouri, she is a general assignment reporter who specializes in social services.

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Politics invade care, critics say

Martinez, Coler accused of gutting watchdog group

By Sandra Mathers

OF THE SENTINEL STAFF

Gov. Bob Martinez and the man he chose to run Florida's social service agency are playing politics with the well-being of thousands of people in personal care homes, say advocates for the elderly.

The advocates point to two developments as evidence of what they believe is a new and repressive political climate under Martinez and Gregory Coler, secretary of Florida's Department of Health and Rehabilitative Services:

Martinez is replacing veteran members of the state's only independent watchdog group for residents of personal care homes, the Long-Term Care Ombudsman Council. The 12-member council lobbies the Legislature on behalf of the elderly and monitors how well HRS enforces the law.

The state council's $142,800 annual budget this year is the same as last year and almost $18,000 less than in 1986-87. In October 1987, HRS for the first time began charging the council $4,000 in annual rent for its space at agency headquarters in Tallahassee.

Martinez's biggest mistake, his critics say, is his replacement of three veteran council members with people less familiar with Florida law and the complex problems of elderly care homes. Others expect to be replaced soon.

That loss of continuity and expertise will weaken the council's efforts to ensure that personal care homes provide good care, said council members and other advocates.

Joseph Martin, president of the Florida Association of Homes for the Aging, wrote the governor in September to warn of "the void that will be created if some of the more active ombudsmen are not appointed for another term."

Martinez was not persuaded. In a recent interview, he said he did not believe that appointing new people to the ombudsman council would hurt the quality of care or have any other ill effects.

"We can never assume that only those who serve have knowledge," Martinez said. "The main thing is you appoint competent people."

But Joyce Raichelson, coordinator of the state council, said it takes members at least two terms — four years — to learn the difficult job of interpreting state law and HRS regulations.

By the time members have become effective advocates, they are no longer eligible for reappointment under Martinez's policy of limiting members of many state advisory councils to two terms.

That's unfortunate for residents of personal care homes, Raichelson said.

"We have found that where you have a visible, effective council, you have a much higher level of care," she said.

But a vocal council, council members say, is precisely what HRS does not want.

The state panel's role of overseeing 12 district councils and improving care for the elderly is a calling that many members interpret as a mandate for outspoken, aggressive lobbying — some of it at odds with HRS.

Most of the state council members expect to be replaced, leaving only two members with a year's experience and no one with the two years necessary to assume the chairmanship.

Among those Martinez has replaced is four-year veteran Virgie Cone of Jasper, a seasoned lobbyist on aging issues.

One who expects to be replaced is Fran Sutcliffe, a retired nurse from St. Petersburg, who has served on the council since it was established in 1975.

"These groups find fault with HRS and (Martinez and Coler) don't like that," said Sutcliffe, 78. She operates a consumer hotline on nursing homes form her home and is considered one of Florida's most knowledgeable advocates for the elderly.

She and her colleagues believe their limited budget is HRS's way of stifling their criticism of the agency. They cite the agency's decision to charge rent, which has forced members to cut back on travel and training.

Raichelson asked HRS Assistant Secretary Margaret Lynn Dugger for a budget increase of $36,000 to make up those and other costs, but she was turned down.

Coler said he was surprised to learn of the council's budget problems. He suggested the head of the council meet with him every three months. "You know how many requests I've had from her this year? Zero," Coler said.

The council's budget problems are no surprise to social service lobbyists.

Several said they recently listened in stunned silence as a ranking HRS official ordered them not to lobby lawmakers for money beyond levels requested by Martinez. Those who do so, some lobbyists were warned later, may end up with less money for their causes.

"We have lost our climate of concern," said Budd Bell, who has lobbied social issues in Tallahassee for 18 years. "We don't have the lovely relationship (with Coler) that we've had with secretaries in the past."

Long worried about their dependence on HRS, members of the ombudsman council are trying to move their offices out of the agency's headquarters in Tallahassee and district offices around the state.

To continue keeping company with the agency they monitor, council members said, creates a conflict of interest.

Coler believes his critics are overreacting.

"We don't control lobbyists," Coler said. Instead, he said, HRS tries to "lead the way by defining the priorities and involving the advocates in it."

Council members and other advocates for the elderly don't believe him. Coler, they said, is trying to enforce two of Martinez's top priorities: no new taxes and more prisons.

And they say that means fewer tax dollars for social services.

JOE BURBANK/SENTINEL

Sandra Godzik feeds Frank Lauria, Dave Caruth at Henry Davis House, one of area's best.

The CHAIRMAN. Thank you, Senator Graham.
Mr. Mike Coonan, from Sacramento, California.

STATEMENT OF MICHAEL COONAN, LONG-TERM CARE OMBUDSMAN, SACRAMENTO, CA

Mr. COONAN. Mr. Chairman, and members of the committee, my name is Michael Coonan. As the last witness, I know my responsibility is to be brief and not to repeat what others have said. I will tell you that the types of abuse that have been presented to this committee are very real and occur in California. In Sacramento we see it every day and it is not going away. It will get worse.

I represent the senior ombudsman advocacy project in Sacramento, California. We are a independent, non-profit organization which operates a substate ombudsman agency which means that we investigate complaints of abuse on behalf of elderly, mentally disabled and mentally retarded people in nursing homes and board and care homes. There are many excellent board and care homes in America. This testimony is not about them.

Recently, we investigated the roles and responsibilities of public and private agencies connected with Dorothea Puente.

Puente was the operator of a boarding house in Sacramento where seven bodies were found buried in her yard. Our report attached to this testimony describes in detail the deadly failures of our illusion of a safety net for elderly.

Unfortunately, the facts show that the failures contributing to the brutal deaths at Dorothea Puente's home are a mirrored reflection of the failures of misguided national policy which fails to protect elderly and disabled people in board and care homes. We expect more murders, rip-offs, abuse, and neglect of elderly and disabled people in board and care homes. As a matter of fact, Social Security Administration policies and procedures encourage and subsidize criminals who murder and steal from these frail, dependent people. For example, most of the residents in licensed and unlicensed boarding houses are unable to manage their own affairs. They are expected by Social Security Administration to find a substitute payee to receive their Social Security or supplemental security income check.

To make matters worse, Social Security Administration does not investigate the backgrounds of prospective substitute payees. This irresponsible indifference encourages people like Dorothea Puente, a convicted felon who had served a prison term for stealing SSI checks from disabled people and who poisoned a senior citizen, to later become a payee. Dorothea Puente was a substitute payee for Bert Montoya, a mentally retarded and mentally ill person, who was murdered and buried in her yard.

What is most troubling about this tragedy is that no one seems to really care about these people. The murders are only a bizarre story which becomes material for mean spirited jokes and fodder for newspaper stories.

What is truly amazing is that thousands of these board and care homes hide in plain sight in cities, in suburbs, and in the rural areas.

How did this happen?

The board and care industry in the United States expanded in direct proportion to the closing of State hospitals. Despite the platitudes of deinstitutionalization and normalization, the driving force to close State hospitals was money. To save money, States closed State hospitals and dumped elderly and dependent people into the community at the same time the Federal Government capped Title XX funding to pay for their community support.

For example, in 1974 the Social Security Administration relieved counties for administering what was known as aid to the totally disabled, the blind, and the aged. Their Social Security and SSI checks were now managed by a computer. County social workers who managed the funds previously and provided casework services for these frail, elderly and disabled people were truly replaced by a button.

Since Title XX funds were capped, the Social Services to protect these dependent people have gradually dried up. Consequently, elderly and disabled people requiring care and supervision must now fend for themselves. If they find a good board and care home, they are lucky. If they find a bad board and care home, they are abused and neglected. Finding a bad board and care home amounts to nothing more than a crap-shoot.

The board and care industry draws many people who are likely to take advantage of frail, elderly and disabled people. All too often, the board and care industry attracts people who have limited education, limited English speaking ability, limited work history, and virtually no knowledge of the needs of the disabled and elderly. In effect, if it's impossible for them to get a decent job elsewhere in society, people in this situation decide to "work with the disabled" and open, or work at, a board and care home!

Residents of board and care homes are left to their own devices to survive. There is little oversight and monitoring of these homes. Public policy has been shortsighted and expedient. The board and care system in the United States is a national disgrace which must be reviewed and reformed. Programs to protect the elderly and the disabled must be funded.

The following are Federal actions that my organization believes will improve the board and care industry in the United States.

One, frail, elderly and disabled individuals determined by Social Security Administration to require a substitute payee must have Federal funds passed through to local jurisdictions to pay for the actual cost of this responsibility. We estimate that is approximately $2 billion dollars a year.

Two, frail, elderly and disabled individuals who require care and supervision in a board and care home must have a significant differential added to their Social Security and/or supplemental security income checks to cover this added cost. Estimated cost is $1 billion.

Three, Federally-mandated long-term care ombudsman programs must be consolidated with Federally-mandated protection and advocacy agencies for developmentally disabled and mentally disabled people. Estimated cost is nothing.

Long-term care ombudsman/advocacy functions must be expanded and fully funded for investigations of complaints of abuse and

neglect of all elderly and adult-dependent people in all licensed and unlicensed board and care homes. Estimated cost is $250 million.

Consolidated ombudsman/advocacy programs must be independent and free of conflicts of interest and must not be housed in multi-service agencies that provide other types of services. Estimated cost is none.

Neglect and abuse of elderly and disabled people is a national disgrace. More frail people will die at the hands of their "caretakers." Our children will either learn from our mistakes or pass on this legacy of neglect. Let us hope that we do not become victims of our children's indifference.

The CHAIRMAN. Thank you, Mike.

Senator Heinz.

Senator HEINZ. There are lots of questions I could ask this group. I will try to be brief.

One question I would like to ask. Anybody in the panel who would like to talk on this—what are the relationships of board and care homes and the residents therein to programs that exist to help the elderly—the visiting nurse services or home health care if you will, Older Americans Act services, meals on wheels, recreational centers and the extent to which the residents of board and care homes are eligible for those kinds of community based services or activities? Anybody have——

Mr. COONAN. Senator Heinz, in California the relationships are casual and hit-and-miss. They are eligible for all of those services but for all practical purposes they are isolated. They are homebound. A remarkable phenomenon that encourages the abuse of these folks is that very few people have an opportunity to see them. That monitoring function of the ombudsman or the licensing people is just a one hour window in a 24 hour day.

Senator HEINZ. In Pennsylvania, are board and care residents eligible for most of those services?

Ms. AFRICA. Yes, they are eligible for many of those services. However, service hours available do not adequately cover the number of needy persons.

Senator HEINZ. And in Ohio, too?

Ms. HINCKLEY. Under the governor's elder care budget package, which has just been introduced to the legislature, the programs that will be involved are the adult protective services through human services, adult care licensing facility and that will be through the Ohio Department of Health, home care ombudsman program and then there are elder care options here that they have listed. It's the information telephone line assistance group referrals, in-home comprehensive assessment, individual service plan, and community based services. This is your respite care, your adult day care, home delivered meals, home maker home aid service, transportation, housing——

Senator HEINZ. I'm talking about the present and not the future. Let me ask Ms. Hinckley. Are your residents, if you know, eligible for example home health care services provided by the State or county.

Ms. HINCKLEY. Yes, we are eligible. It's very scarce to get someone to get someone to come into your home.

Senator HEINZ. True all the way across the United States. I am not questioning the scarcity of those services. I just wanted to establish eligibility.

Second question——

Ms. MURPHY. In New York they are not eligible.

Senator HEINZ. Not eligible in New York?

Ms. MURPHY. No. For almost all the services that are provided, under these titles, residents could go out to get them at a senior center but most of these services are supposed to be provided by the adult home.

Senator HEINZ. Alright. Thank you.

Now, one thing that Ms. Hinckley said that was very interesting. She said that the family doctor would come in and look at the residents to make sure that they get the medical care. She said she wouldn't handle the finances of the resident—that a member of the family did that. In Philadelphia, Pennsylvania, which is about 200 miles from Altoona, but about 5,000 miles from it in many other respects, about two-thirds of the people in the board and care homes of Philadelphia have no family. My question to you is this: what happens when there is no family? Ms. Hinckley's home can do a good job when there is family. What do you do when there is no family?

Ms. HINCKLEY. There are a few services. There is consumer protection that takes over as a representative payee. They can be appointed legal guardian. There are all kinds of people that are willing to do this that can legally handle these finances for them.

Senator HEINZ. Very good.

How about in Pennsylvania?

Ms. AFRICA. In Pennsylvania it is a definite problem. The majority of the operators do take representative payees. For those few who do not, Blair Senior Services, the local AAA, has a very limited amount of payee accounts they maintain. The retarded citizens have a public guardian system. Other than that it's kind of Katie bar the door. It's a giant need and a big question with no real answer.

Ms. Murphy? Mr. Coonan?

Ms. MURPHY. In New York City, as you might imagine, there are not sufficient people who would be willing to act as rep payees.

Senator HEINZ. Is it legal in New York for the operator of the home to be the payee?

Ms. MURPHY. Yes, it is, or an employee or someone like that can act as rep pay. We do have a community guardian program and there could be other mechanisms arranged. Many of the people who are judged in need of rep payees are not. The standards are ridiculous. For example: A doctor writes a letter and says: "My patient cannot manage her own finances and she is 82."

Senator HEINZ. What would happen if it was illegal for the operator or an employee of the operator or any sham transaction for the operator to be in effect the payee.

Ms. MURPHY. Nothing bad.

Senator HEINZ. That would be good or bad? I'm sorry, I didn't hear you.

Ms. MURPHY. That would be very good indeed.

Mr. COONAN. In California we have a prohibition from the operator being the substitute payee for his residents and so they just get their friend who lives next door to be the payee. It gets worse than that. If we have people that are alcoholics or drug addicts the way the process works, they can become the payee for each other. That is really an unfortunate situation. When they go in they can't receive their own check but they can receive their buddy's check and vice versa.

Senator HEINZ. Senator Pryor asked earlier in effect, looking at the video that we saw, why aren't people who have medical problems and physical disabilities that would appear to be beyond the competence of your typical board and care home, why aren't they in a nursing home? Additionally, in part the reason at least in my own State is, there is a shortage of beds for nursing homes. Even so, there is the question of who would authorize the admission to a nursing home if there were? In the case of somebody who does not have family or a family doctor—or something I have been looking for a while—called a family doctor.

Mr. COONAN. That's an excellent question because what is occurring is that one small piece of the puzzle and there are many pieces to this puzzle. We see, in California, that a lot of discharge planners are moving people out of acute care hospitals sicker and quicker into any place they can because of the DRGs and that board and care operators have a fiscal incentive to keep these people in these homes. The weird disincentive is if an operator does a good job and moves somebody to a more independent and higher level of care, they are penalized because they have a vacancy and they don't get that $500 or $600 a month. If they keep them dependent or if they keep them there and they just don't feed them very much, they make a profit.

Senator HEINZ. How do we deal with that?

Mr. COONAN. I'm glad you asked. Thank you.

It is a multi-faceted problem that we need to deal with—a follow along service because many of these people have no relatives. A lot of the elderly people have no relatives. A lot of the elderly people outlive their families. We have to have a placement a more centralized placement function so that we take the operators out of the business of recruiting from everybody in the world to bring people into their homes. We see them going out, wiping out every placement in our county, then they go to the next county and drag folks in. We have to have a better monitoring system which includes both licensing and the ombudsmen to make sure they beef up the ombudsman and really insure that the ombudsman is independent so they can carry out these activities. We are a whistle blower. If you stick us in an agency where we have to call them on the carpet then we're history. You have to make sure that we don't get caught in that situation. We have to communicate with each other. There are law enforcement issues. There are regulatory issues. There are families that need to know what is going on. It is a very secret business. This secrecy prevents people from knowing what is going on.

Senator HEINZ. That was going to be my last question but I want to ask one last, last question, if I may.

The CHAIRMAN. Certainly.

Senator HEINZ. Listening to all of you, Ms. Hinckley to the health people, it would seem that if reasonable people got together as we are today, that you can define a set of solutions that will curb the worst abuses. It may not provide all the money and services that are needed—but it would certainly improve the situation. There has been a very inconsistent effort among States to do that. I assume that political pressures exist for States to ignore these problems. What are the single-most significant political pressures facing States that cause them to make either slightly abhorrent, very abhorrent decisions, or none at all.

Mr. COONAN. Could I just start with that and I won't speak any more. One of the reasons why we are able to survive is because local government has been supportive of our function, whereas the State has been kind of silent and not as supportive. So, if you will look at the arrangement, the closer you get to the ombudsman and the person that intervenes with the people that are elected at the local level with the money coming from another source because we have this buck passing function where everybody else thinks that somebody else ought to pay for it, that if we can consolidate those two activities and establish the independence, you will have a checks and balance system.

Senator HEINZ. Let me ask it more bluntly. The States seem to have largely—there are exceptions—thrown up their hands and are ignoring this problem. Yet, it was a problem that we dumped in their laps in 1976. What are the pressures on the States that keep them from confronting these problems?

Mr. COONAN. The States say the same thing as other jurisdictions: it's not my responsibility. They say it is a Federal responsibility. The State says it is a local responsibility and they keep buck passing. There is no leadership here where somebody says it is my responsibility and we are going to give you the money to do it. That doesn't occur.

Senator HEINZ. Thank you. I think that answers my question. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Senator Heinz.

I agree with Senator Heinz that it appears that the Federal Government has certainly thrown up its hands. The Federal and State governments have essentially given up on this huge problem that affects thousands of people.

Ms. COLEGROVE. Excuse me.

The CHAIRMAN. Yes.

Ms. COLEGROVE. In the State of Ohio presently we are very aggressively addressing the issue and also with legislation that is in the house now to license these homes correctly. Ohio has identified the problem and is moving in a very positive direction with the governor's elder care package.

The CHAIRMAN. I would ask a favor, if I could. If the legislature passes the legislation, we would like to see it. It may well become a model. I hope you will keep us informed of that. In fact, if it doesn't pass, we would like to see it, to see what approach you are making in the State of Ohio.

Yes, Ms. Africa.

Ms. AFRICA. I might offer Act 185 of Pennsylvania, which passed at the end of last year. It is the State's personal care reform act which is just what you are discussing today.

The CHAIRMAN. The committee will be very interested in reading that act. Now this has already passed into law, is that correct?

Ms. AFRICA. That is correct. The regulations have yet to be promulgated.

The CHAIRMAN. I see.

This panel is offering some solutions. My question is this: do we have existing structures out there that we have not talked about? Take for example, the area agencies on aging—are they being brought into this picture? Don't they have a structure that could at least be a part of solving some of these problems?

Ms. MURPHY. As a matter of fact, by passing through the Title III B money to the ombudsman program, they seem to feel that is the limit of their responsibility. I expect there may be political pressure and some disagreement with this kind of testimony that——

The CHAIRMAN. You don't think, for example, the area offices want any responsibility in this field? Is that what you may be saying?

Ms. MURPHY. Yes, sir.

My understanding really is that they see themselves as protectors of people who can live independently in the community and that they have neither the desire nor the ability to protect people outside of that. As Mike pointed out, they are limited by their structure, their political structure. I have found that the pressure that I get through political channels are lessened by the fact that I work for a voluntary agency. My colleagues who work for the AAA agencies directly are not as fortunate.

The CHAIRMAN. What about the State attorney generals? They have, generally speaking, a consumer activist group in each of the respective State AG offices. Could they be involved in overseeing board and care facilities? For example, appoint a citizens' ombudsman tasks force to gather information as to where the board and care homes are. How many exist? How many are licensed? How many are unlicensed? Is that a potential for the attorney generals?

Ms. AFRICA. It is a potential at least in Pennsylvania. Currently, however, it is very difficult to get the attorney general's office interested in board and care. In one instance in Pennsylvania, it took us over two years to get action and attention through that agency in some very heinous situations.

Mr. COONAN. We are attempting to legitimize this ombudsman advocacy function so that it is an independent free standing. Sometimes we have to do some arm twisting with the attorney general. Law enforcement has not been very good in responding to abuse cases of elderly and disabled people. Area agencies have a narrow interest of just the elderly but these homes are housed with mentally ill, mentally retarded people. We are crossing the barriers of all these special interest folks. If you could look at the concept where a State says you shall have an ombudsman—you should make it independent and don't give them a whole lot of money at the State level just give them some support and pass that money on to the counties and let them select and choose how they want to

operate it at that level from our point of view—that will give you more independence.

The CHAIRMAN. I certainly can't speak for all the members of this committee, but I think I know the philosophy of Senator Heinz—we aren't interested in creating a massive new Federal bureaucracy. In fact that may be the worst thing we could do. Somehow or another there has got to be a stronger relationship and partnership between the Federal and State and local governments which does not seem to exist.

Ms. MURPHY. One thing you might ask the attorney generals for are opinions on the State action provisions. One of the problems we found when as advocates, we tried to propose regulations which would link reimbursement to actual services—to penalize people who don't provide good care and reward those who do—was that the current financing mechanism, passing through the money on the SSI limits "State action," and thus limits the State's role. The NYS Department of Social Services said that they could not change the financing. They felt they would be in contravention of Federal as well as State rules. I don't know if that's accurate or not. I just know what the agency told us.

Ms. AFRICA. On the county level currently, we have a personal care home advisory committee which is comprised of all the county agencies that have any interaction with the personal care home industry. We meet regularly. This is not a new bureaucracy. This is something we do voluntarily. We in this way assist not only vertical communication from the county to the State and Federal level, but also horizontal communication on the country level out to the providers.

The CHAIRMAN. Once again, you may be developing a model plan that we want to look at. We would appreciate you sending us a copy.

Ms. AFRICA. It works extremely well. Very well——

The CHAIRMAN. Ms. Hinckley, I have been very fascinated by your testimony. I would like to say that you have done a very splendid job. It appears to me that, from what I know about looking after people who need some care and attention—you are out there living with this problem every day. We come in and talk about it for three hours and then we are worried about the Department of the Defense and the 10,000 other issues. Let me ask this question: have you ever had an ombudsman to come to your home.

Ms. HINCKLEY. Oh, yes, quite a few times.

The CHAIRMAN. Do they come announced or unannounced?

Ms. HINCKLEY. Mostly announced. In my business I have people that pop in and out of my home all day long. I have people that come in to visit these relatives. I don't really put a time frame on visiting hours, or who can come and go. Actually, they come and go as they please, more or less. I just need to know so that I know when to help them or not. I don't think people really know what we do in these group homes.

The CHAIRMAN. Do you prepare your resident's meals, or do you have someone to help? Or, do the residents prepare their own meals? How does that work?

Ms. HINCKLEY. It took me four years to find somebody to come into my home to give me a weekend off. If it wasn't for my mother

helping out, I would have no help. I wouldn't give it up because I really do love what I do, but there are not very many people out there at all who are willing to work with the elderly. When you do find them, they usually don't care about what they want. They are just there to make some money and then get out of there. It's hard to find people who have the patience and understanding to work with older people. It is a big responsibility. It entails a lot more. I could talk forever about it. I don't think people really realize what time we give up and how hard we work. I'm coming to tears here. We work our butts off and nobody acknowledges that. Nobody listens to how we try to get the help. All we hear all the time is how bad we are and how we offer abuse and neglect. I'm telling you that is not true.

If we had some type of regulation at least in Ohio, I know that 90 percent of the abuse would be cut out. I'm that sure of it. I would bet my life on it. I'm sure that if we had more organizations and services in Ohio to come into our homes to teach us how to better ourselves, to teach how to give a proper diet or to give the medication a certain way, or at least let us give medication because we aren't allowed to now anyway—if we had people that would come in and really work with us instead of condemning us all the time and put these black horror stories over us, we could get around half of this.

Everybody here is so worried about what bad things we are doing, nobody is worried about how they can help us. They rattle off that we can do this and we can do that—half you people don't even know what we do. I stay up nights. There are nights that I don't get any sleep. Between my family and my residents, I am bushed. It took me this whole weekend to write this testimony. I'm ready to drop right now. It took me—I have to pay a sitter to come into my home a lot of money. I only charge $500 a month. For me to hire good help to come into my home, it is impossible. It's—I can't afford to pay somebody to come in every day to help me. I wish I could. At the same time, somebody will say give it up. I don't want to give it up. I like what I do. I see how the elderly are being abused. I want to help them.

I don't think people really understand what we do. That's what really makes me sick. I'm listening, taking in everything that everybody here that sits at a desk tells me. I'm thinking: you run a group home and you tell me how good you can do it. You tell me how you can put out three meals a day and get enough rest at night to do this all the time. You tell me how you're going to find the time to locate all these services to help these residents, because if you can find the time I'd like to have you show me how. I can't even find the time to even read a page of a book half the time. Let alone read the newspaper. For me to go to a group home meeting once a month—do you realize that I have to get ready two days in advance to go to a three-hour meeting. I have to make sure that my kids, husband, and home are taken care of; and, I have to make sure that the residents have everything on time. It's a lot of work for one person. To sit here and listen to how all you people can better us—it makes me laugh sometimes. I don't want to come off so crude, but it amazes me how you can sit there and tell me how to do better when half of you people don't even know what we do.

You can only assume. You only see the bad things that we do, not the good that we offer.

Out of all this, what I'm really tired of hearing is what we do wrong. Why don't you get off your butts and help and give us these services? Give us the money that we need and I'm telling you, we can turn it around. We can offer you things that you wouldn't believe.

If you talked to my residents today, all my residents were lined up telling me "Go for it, Pam, get us what you can get" when I left for this hearing. They were all lined up saying, "Hey, Pam, what are you going to do? What are you going to tell them? Are you going to be on TV? We'll be waiting for you." I had one tell me, "I'm going to really miss you, Pam." I said, "I'm going to miss you, too." I know they're missing me right now. I know when I get home they will all be right at my back door waiting for me to walk in that house. Then, I listen to how bad we are—it just overwhelms me how you people with your big words and your fancy statements—I'm this measly care provider and I'm thinking I do more than probably all of you. I feel that way.

There are times when I could just drop because of the things I do. I don't get recognized for that. I only get recognized for what I do bad or what I don't know. That's what really, if anything at all, comes of this. I hope you really do take into account what I have said. I do this for a living. I don't sit here and read books about it and see films about it. I do this for a living.

I welcome the regulations but at the same time I sit here and I think: are you guys going to start popping in whenever you want where I can't even sleep at night or are you going to think that I'm abusing them and try to catch me at something? If you find my dog knocks over a bowl of water on the floor, are you going to cite me for having water on the floor because some resident might trip and fall. Do I have to have my kids—my little boy leaves cars and trucks all over—are you going to cite me for little Tonka trucks being on the floor because it could cause some inhumane damage to the residents? I mean—and from the sounds of some of you people—that's what it sounds like to me. I don't want my home to be totally changed. I am proud of what I do.

The CHAIRMAN. Pam, I tell you what—you don't need to write a speech. You have just given an eloquent speech. I want you to know that I am moved by your statement. I also want you to know that this town right now and this committee, I should say, is looking at the problems—maybe not created by your particular environment in your home—but many others that are not so fortunate to have a Pam Hinckley. These five that live with you are very fortunate.

In fact, I don't know whether this is legal—I may be giving away government property, but I'll get Senator Heinz to loan me enough money to pay for this—I would like to give you this gavel. You take it back to those residents in that home and tell them that we appreciate them and we appreciate you. Thank you very much.

Ms. HINCKLEY. Thank you very much.

The CHAIRMAN. This has been a fascinating morning.

Any final comments? Can any of you all top that?

I think that was an eloquent statement.

All of you have offered constructive solutions here this morning and I'm going to leave the hearing record as I said open for several days and there may be some additional follow up questions, not only from myself but from members of the committee.

Congressman Roybal, who chairs the House Select Committee on Aging, called about two hours ago. He has been trying to get here this morning. He could not. I will have a statement from Congressman Roybal in the record.

[The statement of Mr. Roybal follows:]

NEWS

Select Committee on Aging

U.S. House of Representatives

EDWARD R. ROYBAL, Chairman
300 New Jersey Ave., S.E., Room 712
Washington, D.C. 20515
202/226-3375

OPENING STATEMENT

JOINT HEARING BEFORE THE SENATE SPECIAL COMMITTEE ON AGING,

HOUSE SELECT COMMITTEE ON AGING, SUBCOMMITTEE ON HEALTH

AND LONG-TERM CARE, AND THE SUBCOMMITTEE ON HOUSING

AND CONSUMER INTERESTS

ON

"BOARD AND CARE HOMES IN AMERICA: FAILURE IN PUBLIC POLICY"

Chairman Edward R. Roybal
Select Committee on Aging
March 7, 1989

Good Morning. As Chairman of the Select Committee on Aging, I applaud my Subcommittee's initiative in pointing out the abuses in board and care homes. This morning we will hear from a number of witnesses with terrifying and shocking stories of abuse which they have suffered. The abuses are horrid and unacceptable. Clean, affordable and non-abusive housing must be attained for all elderly, especially those who are frail,vulnerable and have few other options.

Clearly, we must get rid of the abuses. No society should allow people to stay in an environment as described by those here today. But, no board and care home should be shut down without an alternative in place. These residents are in a difficult situation. The federal government must live up to its share of the responsibility in caring for these people. Regulation without fiscal participation will leave these people in the cold," said Roybal.

I would however, like to caution my colleagues from condemning an entire industry for the abuses of a few. This approach overlooks the need to recognize this type of housing as a critical, and large part of this nations available housing and long term care services. Board and care homes, if clean and safe are a creative alternative to inappropriate institutionalization of low-income, frail elderly and handicapped people.

There is a critical need to examine the serious abuses in these homes. It is important to establish the extent to which this is a systemic problem in board and care homes and if so how will we be a part of salvaging the industry so that it can be a respectable part of the long-term care housing options for the elderly and handicapped.

Board and Care homes provide shelter and services for over 563,000 people in 41,000 homes, and probably closer to 1 million Americans. We can not do without them and we can not ignore the problems that continue to exist.

We, the federal government have attempted to prevent abuses since the early 70's. First using the Keys Amendment to the Social Security Act in 1976, to reduce SSI benefits to residents who lived in homes which where not in compliance with states minimum standards. Then the Rinaldo Amendment to the Older Americans Act, passed in 1981, which required board and care homes to be part of the Long-Term Care Ombudsman Program in each state. The Ombudsman oversight was strengthened in the 1987 OAA reauthorization.

Unfortunately, these measures were not enough to significantly provide safeguards for residents of board and care facilities. The following is a brief list of some of the problems that exist along with the abuses:

- o Inadequate federal oversight and protection.
- o No standard definition of homes.
- o No data to accurately identify unlicensed homes.
- o Few private or public options other than board and care for housing and services.
- o A need for training and education of operators.
- o No uniform regulatory standards for board and care homes.
- o Massive red tape for operators trying to license their facilities.

We can not go back to simply looking at the abuses of the industry and blaming the entire industry for their lack of success in preventing any abuses. We must go beyond this. We must seek out ways to improve this important part of the long-term care continuum. Board and care homes provide shelter and services for hundreds of thousands of Americans. The federal government must seek out a proactive path to aid the residents, the operators, and the states in providing quality housing and services for our frail, low-income elderly who have few other options.

The federal government needs to take a serious, complete look at this industry and determine how board and care homes can effectively be monitored and regulated to protect the safety and welfare of the elderly.

The CHAIRMAN. Now we will turn to the General Accounting Office. We thank this panel very much.

Senator HEINZ. Mr. Chairman, while the GAO is coming forward and our witnesses are being excused, I just want to commend and associate myself with your last comments and with your presentation to Pam Hinckley.

The CHAIRMAN. Thank you.

Senator HEINZ. I might just add that, as I mentioned earlier today, I will be working with you and other members of the committee to develop a legislative proposal that I think will be sensitive to the concerns of the responsible providers such as Ms. Hinckley as well as to the concerns of the ombudsmen and other officials that have to make this work.

The CHAIRMAN. Very good. Thank you, Senator Heinz.

Ms. Janet Shikles is Director of Public and National Health Issues, Human Resources Division of GAO. She is accompanied by Mr. Alfred Schnupp, Assignment Manager, and Mr. Chris Rice, Evaluator-in-Charge.

We want to first commend the General Accounting Office for this outstanding report. I guess none of us would have been here today without this report because it has become a central focus of what this hearing is all about. You have been very, very helpful in offering it to us.

Do you have a statement, Ms. Shikles?

STATEMENT OF JANET L. SHIKLES, DIRECTOR, NATIONAL AND PUBLIC HEALTH ISSUES, HUMAN RESOURCES DIVISION, GENERAL ACCOUNTING OFFICE, ACCOMPANIED BY ALFRED SCHNUPP, ASSIGNMENT MANAGER; CHRIS RICE, EVALUATOR-IN-CHARGE

Ms. SHIKLES. Yes, Mr. Chairman. I will just summarize my statement.

As you have already stated, residents in board and care homes include some of the most vulnerable members of our society. Assurance that these residents are not mistreated or are not placed in a life-threatening situation is primarily a State responsibility; however, we found that States establish their own requirements regarding the type and size of board and care homes and the kinds of services that have to be provided.

We also found that this is quite variable among the States. A home that must be licensed to operate in one State can legally operate without being licensed in another State.

We also found that State inspections tend to focus on the physical plant; how aggressively the States enforce their regulations also varies. For example, two of the States that we visited in our review, Ohio and Texas, made almost no attempt to locate and license homes.

In addition, regardless of the regulatory effort made by the States, most officials that we interviewed expressed concerns about the adequacy of their oversight of board and care and almost all officials told us that they didn't have enough resources or enough staff to inspect homes.

As you have already heard today, State inspections continue to find very serious problems. These range from such situations as physical and sexual abuse to persistent unsanitary conditions, such as trash and improperly stored food. We found that in some cases board and care residents have been denied heat, did not receive needed medical care, were suffering from dehydration, or had food withheld if they did not work. We also found that in some situations problems have occurred which contributed to the death of board and care residents.

As you also heard from the previous panel, serious conditions and problems exist in unlicensed homes.

While none of the six States we visited had aggregated inspection data, officials believe that most of these problems are concentrated in homes with low income residents, specifically those who rely on SSI for support.

What is a particular concern is that in spite of the difficulties States are experiencing in making sure that their residents receive appropriate care in board and care homes, we found that HHS has committed few resources to oversight of this industry. For example, the Keys amendment required States to certify annually to HHS that all those in facilities in which a significant number of SSI residents reside or are likely to reside receive appropriate care. Last year, only 25 States sent in these certifications to HHS. In addition, two of the States which sent in certifications were Ohio and Texas; however, in our reviews officials in both of those states have acknowledged that they have not aggressively licensed or enforced their regulations, and that thousands of unlicensed homes continue to operate. State officials also acknowledge that SSI residents are in these homes.

At a 1981 Congressional hearing on the board and care industry, HHS came to Congress and raised concerns about its lack of regulatory authority. However, at that same hearing the Under Secretary said that HHS did not support the repeal of Keys. Instead, HHS officials promised that they would go back and develop proposals for the Congress to implement to assure some protection for board and care residents.

The CHAIRMAN. In what year was this, please?

Ms. SHIKLES. In 1981.

HHS never came back to Congress with these proposals.

In conclusion, board and care homes serve, as you have heard, a very vulnerable population which has been subject to neglect and abuse for too long. It is clear that current policies are not offering sufficient protection to these residents and that a national strategy is needed to assure that residents do receive appropriate care.

Mr. Chairman, this concludes my statement. I would be happy to take any questions.

[The prepared statement of Ms. Shikles follows:]

Statement of
Janet L. Shikles, Director of
Public and National Health Issues

We have recently completed our report on the board and care industry which we prepared in response to a request from the Senate Special Committee on Aging and House Select Committee on Aging.[1] This request was prompted by your concerns about the quality of care provided to residents in some board and care homes. Our review focused on six states--California, Florida, New Jersey, Ohio, Texas, and Virginia--and the Department of Health and Human Services (HHS). We are pleased to be here today to discuss our findings.

DEFINITION OF THE INDUSTRY

To start, there is some confusion about what constitutes the "board and care" industry. This is because board and care homes go by a variety of names, which vary across states and within communities. The public may instead know these homes as adult homes, group homes, personal care homes, or rest homes. What distinguishes board and care from other facilities is that they provide, in addition to a room and meals, some degree of protective oversight.

RESIDENTS HAVE SPECIAL NEEDS

Residents in board and care homes include some of the most vulnerable members of our society. Many have physical limitations, and a large number have previously lived in an institution for the mentally ill or the mentally retarded. Many need help in taking medications and managing their money. And few have relatives or friends to visit them to make sure they are getting the care they need. One very serious problem for board and care residents is that so many have incomes at or below the poverty level; in fact, a large number depend on Supplemental Security Income (SSI) for their support.

RESIDENTS' PROTECTION
NOT ADEQUATE

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[1]U.S. General Accounting Office, Board and Care: Insufficient Assurances That Residents' Needs Are Identified and Met (GAO/HRD-89-50, Feb. 10, 1989).

Assurance that board and care residents are not mistreated or placed in a life-threatening situation is primarily a state responsibility. States establish their own requirements regarding the type and size of board and care homes that must be licensed and what services must be provided. This is highly variable--a home that may have to be licensed in one state could legally operate without a license in another.

State inspections of the industry tend to focus on the adequacy of the physical plant; also, states vary in how aggressively they enforce their licensing requirements. For example, two of the states we visited, Ohio and Texas, made almost no attempt to locate and license homes. Hence, a large number of homes in those states (an estimated 3,500) are unlicensed and unregulated. In addition, regardless of the regulatory effort made by the states, most officials we interviewed expressed concerns about the adequacy of their oversight of board and care homes because of insufficient resources and staff.

States also operate ombudsman programs that have varying degrees of oversight over board and care homes. The ombudsman program was initially created to look into nursing homes, but in 1981 the Congress expanded it to include complaints of board and care residents. However, no additional funds were provided for these added responsibilities. In 1987 a survey of all state ombudsmen found that about half believed that they had not been successful in assuring coverage of residents in board and care homes.

State inspections of licensed board and care homes over the past several years have identified that a wide variety of problems continue to exist. These range from very serious situations, in which residents have been subjected to physical and sexual abuse, to problems involving persistent unsanitary conditions, such as improperly stored food and trash. In some cases board and care residents had been denied heat, were suffering from dehydration, were denied adequate medical care, or had food withheld if they did not work. Situations have also occurred that contributed to the death of board and care residents.

Serious problems also exist in unlicensed homes. For example, in Ohio a state health department nurse found residents in unlicensed homes who were not receiving enough food or who had large lesions, bedsores, and unattended chronic infections. While none of the six states we visited had aggregated inspection data, officials believe that problems are predominantly concentrated in homes with low-income residents, specifically those on SSI.

When states find that the residents' safety or well-being is threatened, they have the legal authority to immediately close a home or suspend its license. In situations that involve poor quality care, however, three of the six states in our review had only one sanction available--to deny or revoke a home's license. For these states, this is a time-consuming process that can take up to a year. The other three states had intermediate sanctions, such as fines or receivership.

A major constraint facing states is the lack of alternative housing, especially for those residents who rely on SSI and other forms of public assistance. Because SSI support is often below the operators' costs to provide care, some homes refuse to admit SSI residents; other homes that used to admit low-income residents have closed. This has resulted in a shortage of beds in some areas.

HHS HAS PROVIDED NO LEADERSHIP

In spite of the difficulties states are experiencing in assuring that residents in board and care homes receive appropriate care, HHS has committed few resources to oversight of this industry. In 1976, the Congress enacted the Keys Amendment to the Social Security Act to protect SSI recipients from living in substandard homes. States are required to certify to HHS that all facilities in which a significant number of SSI recipients resided or were likely to reside met state standards that would assure appropriate care. These standards were to cover such matters as admission policies, sanitation, safety, and protection of civil rights.

States must annually certify to HHS that they are in compliance with the Keys Amendment. However, in fiscal year 1988, HHS received certifications from only 25 states. In addition, two of the states that sent in their certifications to HHS that they are in compliance with Keys were Texas and Ohio. Yet officials in both states acknowledged to us that they may have thousands of unlicensed and unregulated homes and that many of these homes are likely to have SSI recipients. HHS officials noted that there are no penalties if a state fails to certify compliance with Keys. We also found that HHS is committing only a portion of one person's time to reviewing state certifications and summaries of standards.

The implementing regulations of the Keys Amendment also require states to periodically inspect and report deficient board and care homes to the Social Security Administration so that the agency can reduce SSI benefits of any recipient living in such homes. According to our survey of 10 SSA regional offices, only eight states have ever reported substandard homes. Because this provision penalizes the recipient for the facility's failings, states have little incentive to report board and care violations to SSA. Two SSA regional offices found that most states they contacted claimed to have no noncomplying facilities.

At a 1981 congressional oversight hearing on board and care, HHS noted its concerns about the limitations of federal authority and the weakness of the Keys Amendment. At the same hearing the undersecretary also assured the Committee that HHS did not support the repeal of Keys. Instead, officials agreed to find a way to make the amendment more effective, including developing legislative recommendations. However, HHS never developed proposals to revise Keys.

In conclusion, board and care homes serve a very vulnerable population, which has been for too long subject to neglect and abuse. It is clear that current policies are not offering sufficient protection to these residents and that a national strategy is needed to assure that residents are adequately protected. To develop this strategy, HHS will need to exercise strong leadership both to assess the problem with current regulatory efforts and to identify what options exist to improve these efforts. Consequently, we are recommending that the Congress direct HHS to

-- conduct a comprehensive assessment of each state's oversight activities for its board and care population. This assessment should determine the adequacy of (1) licensing and regulatory requirements, (2) resources committed to their enforcement, and (3) efforts to identify whether residents' needs are being met.

-- report the results of this assessment to the Congress together with recommendations as to what steps are needed to assure the protection of board and care residents and what changes are required to the Keys Amendment to make it more effective.

Mr. Chairman, this concludes my statement. I would be happy to answer any questions that you or members of the Committee may have.

The CHAIRMAN. I wonder if Mr. Rice or Mr. Schnupp would have any follow-on comments? You are welcome to give those comments, should you desire.

Mr. SCHNUPP. Yes, sir. I would like to comment on one of the problems with Keys.

In setting up the legislation, it said that homes should be regulated where "a significant number" of SSI residents reside. That has never been defined. The regulations of HHS have basically left that up to the States to define "significant number." So what you end up with is—for example, in Ohio only homes with six or more residents have to be licensed, whereas California licenses all homes with one or more residents.

So here we have a Federal law that is supposed to protect all residents in the country; yet, if you would take the homes in Ohio that don't have to be licensed and move them across State borders and put them in California, those same homes would have to be licensed.

So I think one of the problems you have to deal with is clarifying what we mean by "significant number" so that at least we could have the same basis across all the States as to what we're talking about when we license board and care homes.

The CHAIRMAN. What is conceivably the Federal hook where we can have some regulatory jurisdiction? Is it the SSI payment?

Ms. SHIKLES. That's the problem. There really is no Federal hook right now, and I think that's why some of the proposals that you have in your report that you are issuing with this hearing would add to that Federal hook.

The CHAIRMAN. Do you have any idea why—and I know this requires a subjective answer or opinion—since 1981, after HHS promised to come forward with some recommendations or regulations, they did not?

Ms. SHIKLES. I really don't. They initially explored some recommendations. They were looking for a Federal hook. At one time they were going to tie some penalties to the Older Americans Act programs if the States didn't enforce the regulations. They decided not to do that.

I think it was really the intent of the Secretary of HHS at that time to do something, but then all the initiatives died out when he left his position.

I think there is also a lot of concern that any proposal that department officials present to the Congress will require increased Federal appropriations. This is because the real issue here is spending more Federal money because we do need more regulations and we do need Federal standards. Almost anyone who looks at this industry feels that we've got to spend more money if we're going to get better care.

The CHAIRMAN. The GAO report—this particular report, requested by Mr. Pepper and Senator Heinz—is probably one of the only really thought-provoking studies that has been done on this in recent years. It looks like we're starting at ground zero here.

Ms. SHIKLES. Right. Almost no research has been done since the very early 1980s. When we tried to do the work, we couldn't get a handle on what the size of the problem is. You can't get an overall

picture because there has been so little done. There is almost no effort going on at HHS. They really haven't looked at this issue.

The CHAIRMAN. One thing that has been a problem—is, has, and will be a problem—is, let's say that a home has been cited for some unfair treatment or abuse. So you say, "Okay, you're going to pay a $1,000 fine, or we're going to close you down." Most of them probably can't pay a $1,000 fine, so you close it. So you end up with two, three, five, ten, twelve people out on the street——

Ms. SHIKLES. That's right.

The CHAIRMAN. The penalties and sanctions are so critical here and there's such a void of any real answers as to how we formulate those sanction. We've had the same problem with nursing homes for 20 or 30 years. It looks to me that maybe 30 years ago the nursing homes were about where some of the board and care homes are today. As an analogy that may be too simple, but——

Ms. SHIKLES. I think it's probably close.

The CHAIRMAN. Mr. Rice, did you have any comments?

Mr. RICE. I think you made a very good point, sir, that the board and care industry may very well be in the same situation that the nursing home industry was in 25 or 30 years ago in that there are no Federally-mandated standards for the board and care homes, as there were none for the nursing homes years ago. There are no Federally-mandated inspection requirements such as you now have for Medicare and Medicaid.

So I think you have made a very good point that the nursing home industry of 30 years ago may be reflective of what we're facing now in the board and care industry.

The CHAIRMAN. I just want to make it very clear once again that today we have looked at the problems. Many of them have been highlighted in your report, and in Senator Claude Pepper's March 1989 report. With these two reports, I hope we will have a launching pad to start a national dialogue on the problems and solutions of board and care.

I want to thank the three of you. You've done an excellent job, as the General Accounting Office does. I have said in many hearings that if the General Accounting Office ever closes up we might as well close up the Federal Government. We don't know what we'd do without you. Thank you very much.

Ms. SHIKLES. Thank you.

The CHAIRMAN. The hearing is adjourned.

[Whereupon, at 12:49 p.m., the committees were adjourned, to reconvene at the call of their respective Chairs.]

APPENDIX

Item 1

United States Senate
SPECIAL COMMITTEE ON AGING
WASHINGTON, DC 20510-6400

BOARD AND CARE HOMES IN THE UNITED STATES:

FAILURE IN PUBLIC POLICY

A staff briefing paper prepared for the

U.S. SENATE SPECIAL COMMITTEE ON AGING

DAVID PRYOR, Chairman

JOHN HEINZ, Ranking Member

U.S. SENATE SPECIAL COMMITTEE ON AGING

STAFF BRIEFING PAPER

BOARD AND CARE HOMES IN THE UNITED STATES: FAILURE IN PUBLIC POLICY.

Introduction.

In addition to providing important housing options for the poor and disabled, board and care homes have come to occupy a key niche in the American long-term health care system. In this role, board and care operators provide less intensive nursing care than a nursing home, but more monitoring and supervision than is feasible for many elderly and disabled persons living independently at home. The importance of board and care homes to the continuum of long-term care, particularly, has grown as governmental reimbursement strategies have shifted care of the elderly out of expensive institutions and into nursing homes and community-based care settings.

Remarkably, board and care facilities evolved this key role almost entirely in the absence of governmental monitoring and reimbursement. As a result, a situation has developed which is both ripe for abuse and exploitation of isolated and vulnerable adults, and fraught with frustration for the well-intended, but overwhelmed, caregiver. Problems will worsen under current trends. In addition to the pressures brought by a steadily growing elderly population, implementation of the nursing home preadmission screening provisions of the 1987 Omnibus Budget Reconciliation Act is likely to increase the reliance of chronically ill, mentally ill and mentally-retarded nursing home residents on board and care providers in the United States.

Background.

"Board and care" is a catch-all term used to describe a wide variety of non-medical residential facilities, including group homes, foster homes, personal care homes and rest homes. The General Accounting Office (GAO) found that they are typically located in cities, have an average of 23 beds or less, and are privately operated.

Board and care homes are an important and often overlooked component of the continuum of long-term care. Board and care homes provide care for poor and disabled individuals -- often mentally ill -- who reside in board and care homes because they can no longer take care of themselves and frequently because they have no place else to go. State surveys show that 90% of residents remain over 6 months, and two-thirds stay for over 12 months, in these facilities. As in nursing homes, residents are unlikely to have friends or relatives who visit them on a regular basis. The needs of board and care residents range from needing assistance with shopping, housekeeping and/or preparing meals (30% to 56%), to needing assistance with bathing, dressing, eating and/or taking medications (27% to 43%).

While board and care homes provide essential long-term care to thousands of older and disabled Americans, generally neither private nor public health insurance -- including Medicaid -- pays for care received in these facilities. As a result, to an even greater extent than in nursing homes, out-of-pocket payments are the primary method of paying for the personal care provided in board and care homes.

The burden of financing board and care falls heavily upon the predominantly poor residents of these facilities: 51% of the elderly, 64% of the mentally ill, and 78% of the mentally retarded living in board and care homes pay for their care with their meager income ($368/month for a single person in 1989) from the federal Supplemental Security Income (SSI) program. About half of the States provide a supplemental payment to SSI recipients, averaging about $200/month for a single person.

In 1976, in response to concern about problems in board and care homes, Congress enacted the Keys Amendment to the Social Security Act. It required states to certify to the Department of Health and Human Services (HHS) that all facilities with SSI recipients as residents met certain general standards. A 1987 survey of licensed facilities identified about 41,000 licensed homes, with about 563,000 beds serving the elderly, mentally ill and mentally retarded. Of this amount, about 264,000 beds were identified as serving only the elderly. Data are not available on the number of unlicensed homes, although it is generally acknowledged that a greater number of homes are unlicensed than licensed. For example, in its investigation, GAO estimated that 3,500 unlicensed facilities -- compared to 330 licensed homes -- are operating in Texas and Ohio.

Problems in Board and Care Facilities.

PROBLEM #1: Despite previous congressional hearings to bring board and care homes into compliance, homes still lack adequate fire escapes, cleanliness, nutrition standards. Examples:

- o According to one veteran board and care home inspector, residents are routinely locked into their rooms.
- o Non-ambulatory residents have been found living on the second floor and in the cellar of some facilities. In one unlicensed facility in Ohio, a double amputee was found tied into his wheelchair, with his fire escape route locked.
- o GAO reported that inspectors in one facility found trash, dirty carpets, urine odor, insufficient and improperly labeled and stored food and medications, a dirty and inoperable stove, no toilet paper, flies, and no heat.

PROBLEM #2: Board and care providers overuse and misuse medications, and inadequately supervise the dispensing of medications.

- o An Ohio inspector observed "multiple antipsychotic drugs administered to keep residents sedated so that the caregiver will not be bothered. Many of such residents do not even have a primary or secondary diagosis of mental illness".

- o In Pennsylvania, a provider was found using residents' prescription sleeping pills and sedatives interchangeably among residents, without regard to whether a doctor had prescribed a particular medication for a resident.

- o At an unlicensed facility in Ohio, a female resident was receiving 27 medications each day, including a triple dose of a powerful dehydrating agent.

- o In Philadelphia a mentally retarded resident in a board and care home was repeatedly hospitalized after she received high doses of medication that was not prescribed for her condition -- a mentally ill resident had been allowed to dispense her medications.

- o A study of North Carolina board and care homes found an average of 5.8 drugs being taken by those residents with at least one prescribed medication. The antipsychotic agent haloperidol ("Haldol") was the most frequently used prescription drug in these homes.

- o A study of Massachussetts board and care homes found 39% of residents received at least one powerful antipsychotic drug. About half of residents had "no evidence of participation by a physician" in decisions about their drug therapy, while facility staff "revealed a low level of comprehension of the purpose and side effects" of these drugs.

PROBLEM #3: Many board and care home residents' basic personal care needs are neglected.

- o A resident of a Florida board and care home was admitted to a hospital weighing 54 lbs -- 52% of her ideal body weight. It was found that the resident required assistance eating and the provider neglected to help her.

- o In Ohio, a veteran inspector noted, "I have observed elderly with multiple bedsores which had not been under the care of a physician. In one instance I counted 32 bedsores on one small woman. These sores were infected and draining purulent material. In another instance I observed a bedsore that measured 14 inches. This sore was down through all the muscles to the bone."

- o A California inspector noted: "An elderly woman, who was lying on a bed in a room at the back part of the facility, had her genitals exposed, she had a decubitus [bedsore] stage 3 and 4 on each hip, she was dehydrated, she was unable to swallow....Her arms and legs were drawn up tightly to her frail body. She was unable to speak, eat or move....She had no diaper on and she was lying in feces and urine. Her fingernails had not been cut or cleaned for some time."

- o Control of incontinence is often done inappropriately by use of indwelling catheters. All catheters observed in unlicensed board and care homes in Ohio showed "purulent mucous plugs [and] tubing encrustation...which are signs of infection of the lower urinary tract."

PROBLEM #4: Many board and care residents require more care than the operator is competent to provide.

- o Residents requiring 24 hour nursing care are sometimes not discharged to a hospital or nursing home for care, resulting in suffering and preventable deaths.

- o In Alabama, a homeless man who was hospitalized after being injured in an automobile accident, was found to have a decubitus ulcer, and to be suffering from dementia and malnourished. Though eligible for Medicaid paid nursing home care, he was refused by the nursing home and instead placed in a board and care home.

PROBLEM #5: Residents with special care needs, such as Alzheimers' Disease victims and the mentally ill, often do not receive appropriate supervision and care. For example:

- o In Pennsylvania, some board and care operators do not allow mentally ill and retarded residents out to attend community programs designed for their needs.

- Young mentally ill residents have physically and verbally abused elderly residents, according to an official in Florida.

PROBLEM #6: Board and care residents are often financially exploited.

- In Vermont, an elderly resident suffering from Alzheimer's Disease would pay the board and care home rent each time the owner told the resident that rent was due. The owner collected rent from the resident 2-3 times a month by saying rent was due when it had already been paid.

- In Florida, a board and care home operator stole $85,000 from a 94 year old resident after promising to invest it for him in a pension fund.

- In Arkansas, a board and care provider convinced an elderly woman to delete her husband's name from over $300,000 in securities and replace his name with the provider's, resulting in losses to husband in excess of $100,000. The same provider allegedly stole over $100,000 from another resident.

PROBLEM #7: Some board and care operators evidence such poor character that they are clearly unqualified to care for the elderly and disabled.

- A Pennsylvania board and care operator physically and verbally abused residents. On one occasion the operator verbally abused a male resident who had lost control of his bowel, while the resident lay on the floor, helpless and unable to resist.

Causes of Current Problems in Board and Care Homes.

CAUSE #1: States have failed to establish adequate licensing, inspection and enforcement standards for board and care homes.

- GAO estimates that anywhere from 500,000 to 1.5 million boarding home residents are living in homes that should be licensed as board and care homes.

- States assign up to 200 licensed homes to one inspector, for annual and, in some states, semiannual inspections.

- States rarely punish substandard providers as provided under federal law -- reduction of the SSI benefits of recipients living in a substandard board and care home -- because this unduly penalizes residents. But half of the States GAO examined have yet to enact an alternative enforcement authority, such as the power to impose civil monetary penalties.

- There is no federal requirement that State licensure programs must be equipped with authority to impose civil fines and other basic powers possessed by State nursing home licensure programs.

CAUSE #2: The Department of Health and Human Services has failed in its statutory responsibility to monitor State enforcement of quality standards in board and care facilities.

- The 1976 Keys Amendment requires states to establish and enforce board and care standards, and requires HHS to monitor State compliance, but HHS currently allocates only one-eighth of one person's time to check that States have mailed in their certifications.

- Some States have failed to file the required annual report with HHS, and others have falsely reported full compliance with federal law, without adverse action by HHS.

CAUSE #3: The absence of public or private insurance to reimburse the cost of personal care services in board and care homes jeopardizes access to quality care for the low-income elderly and disabled.

- Over half of all residents of board and care homes are dependent upon federal low-income support payments under the Supplemental Security Income (SSI) program to pay for room, board and personal care services in board and care homes.

- o SSI payments make no allowance for the cost of personal or nursing care required by recipients. SSI recipients are eligible for Medicaid, but this program seldom pays for board and care home services.

- o GAO found that homes serving predominantly SSI recipients had about twice as many violations as homes serving predominantly private-pay residents.

- o 22 states provide no supplements to SSI recipients in board and care homes. Where supplements are paid, supplements are available only to residents of licensed homes, and they may be inadequate to cover the cost of personal care:

  - Florida provides SSI residents with $694 a month, including a State supplement, but Florida board and care homes charge an average of $790/month.

  - A 1987 New Jersey survey revealed that SSI payments, including a State supplement, fell $200 dollars short of the average monthly cost of caring for residents.

  - Pennsylvania board and care residents receive $650/month in combined State and federal SSI payments, but the average board and care facility charge in 1988 was over $760/month.

CAUSE #4: There is a lack of training and education among care providers in board and care facilities, often leaving providers ill-prepared to care for the needs of frail elderly or chronically mentally-ill residents.

- o Some providers are unable to recognize when patients need a higher level of care, resulting in inadequate care. This is a particular problem for those who care for older residents who are "aging in place" -- becoming increasingly frail and in need of nursing care.

CAUSE #5: In an effort to control costs, the Medicare program and various States' Medicaid programs have attempted to move patients into the lowest possible level of care at the earliest opportunity.

- o Board and care home providers report hospitals discharging patients in need of skilled rehabilitation care directly to the board and care setting.

- o Pennsylvania's legislature has just passed a law that will allow non-ambulatory residents to remain in board and care homes -- whereas previously such patients required nursing home care.

CAUSE #6: In the absence of any case-management and coordination of long-term care, decisions about where a person receives care are left up to providers. Resulting conflicts of interest impede access to appropriate nursing and medical care.

- o Nursing home bed shortages, coupled with nursing home operators' preference for private paying patients, make it very difficult for board and care operators to transfer more seriously ill SSI recipients to nursing homes.

- o Some providers are unwilling to discharge residents who need more care for fear of losing a paying resident.

CAUSE #7: Board and care residents are often isolated and vulnerable without the protection offered by family, friends, ombudsmen or state regulatory oversight.

- o Many residents do not have family or friends who visit them regularly; as a result, they are often isolated and without a "watchdog" for their rights.

- o Although long-term care ombudsman advocates are charged with the responsibility to visit board and care facilities, many find that their limited funds only permit them to focus on the nursing homes in their jurisdiction.

Policy Options for Reforming Board and Care Homes.

Financing Board and Care:

OPTION #1: Include personal care services (assistance with bathing, dressing, eating, ambulation/transferring, etc.) provided in licensed board and care homes in the array of services reimburseable under any federal long-term care program enacted by Congress.

OPTION #2: Add personal care services provided in licensed board and care homes to the list of mandatory State Medicaid services.

Monitoring and Enforcement of Standards in Board and Care:

OPTION #3: Specify minimum enforcement powers States must enact and use on substandard board and care operators. If a State fails to enact and/or use these powers, the Secretary would withhold up to 5% of federal matching funds for the State Medicaid agency's administrative costs. The minimum enforcement authority includes:

- o Power to conduct unannounced onsite inspections of both licensed and suspected board and care providers.
- o Licensure required for all facilities where unrelated residents require personal care (with sliding fee scale).
- o Power to impose directed plan of correction.
- o Civil monetary penalty authority.

OPTION #4: Require States to establish minimum health, safety and security standards for licensed board and care operators. A State failing to enact and enforce standards at least as demanding as the federal minimums would be subject to the administrative penalty described above. Federal law would specify minimum standards in the following areas:

- o Structural safety, such as fire/emergency preparedness.
- o Sanitation, such as safe disposal of infectious waste.
- o Safe and appropriate provision of personal care, when provided to a resident.
- o Safeguards against providing services the board and care operator is not competent to provide (such as nursing, rehab).
- o Code of residents' rights.

OPTION #5: Increase funding to States for expanded inspections, including:

- o Annual inspections.
- o Complaint inspections within 10 days of receipt of complaints.
- o Crash program to identify unlicensed board and care homes.

OPTION #6: Expand resources of Long-Term Care Ombudsman program for board and care home monitoring and resident advocacy; clarify right of access to residents of ombudsman advocates.

Support for Board and Care Operators:

OPTION #7: Make federal loan guarantees available to licensed operators to help them obtain funds for upgrading the physical plant of board and care facilities.

OPTION #8: Direct the Secretary to enter into contracts to provide training and support for providers:

- o Contract with one or more national organizations to develop a training curriculum including first aid, basic CPR, and personal care skills, for use in preparing caregivers to become board and care operators.
- o Contract with State or local entities to provide ongoing continuing education, advice, and respite for B&C operators.

Item 2

SURROGATE DECISIONMAKING FOR ADULTS: MODEL STANDARDS TO ENSURE QUALITY GUARDIANSHIP AND REPRESENTATIVE PAYEESHIP SERVICES

A REPORT

BY

THE CHAIRMAN

OF THE

SUBCOMMITTEE ON
HOUSING AND CONSUMER INTERESTS

OF THE

SELECT COMMITTEE ON AGING
U.S. HOUSE OF REPRESENTATIVES

INTRODUCTION

Independence, self-determination, autonomy -- these concepts are fundamental to our nation's political philosophy and are basic tenets of United States citizenship. Yet, more than 500,000 adult citizens[1] are denied basic rights to make decisions and exercise control over their own person and/or property. The denial of these rights is the consequence of a court determination that an individual is legally "incompetent" or "incapacitated" and the appointment by the court of a guardian to act as surrogate decisionmaker on the person's behalf. The real tragedy is that mounting evidence suggests that many of these individuals -- having been stripped of their right to self-determination -- are being poorly served, and even victimized and exploited by the very persons or agencies appointed to protect them and to make decisions on their behalf.

While much has been written about the inadequacies of the system for determining legal incompetence and appointing guardians, only recently has attention been focused on the performance of guardians once appointed. To date, this attention has focused almost exclusively on describing problems and abuses in the provision of guardianship services. Compelling evidence signaling the seriousness of problems has come most recently from the national study and series of articles by the Associated Press (AP).[2] The study results indicate an urgent need to address issues of quality control in the provision of guardianship services. The AP expressed particular concern about the growing number of agencies and professional service providers -- both public and private, nonprofit and for-profit -- receiving compensation to provide guardianship services.

In response to the AP series published in September of 1987, there was a call from prominent advocates for the elderly in Congress, state legislators and judicial officers, and numerous others, for standards against which the quality of guardianship services might be measured. Unfortunately, very few efforts have been made which go beyond a delineation of problems and attempt to deal in concrete terms with issues of quality control and standards of practice.

The Center for Social Gerontology (TCSG) is one of the few to have undertaken development of standards for providers of guardianship services. The TCSG standards, which were originally developed for the State of Michigan, have been adapted and modified for The Subcommittee on Housing and Consumer Interests of the House Select Committee on Aging for national use. TCSG is very grateful to the Subcommittee for this opportunity to disseminate the proposed model standards and to urge their adaptation and implementation nationwide.

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[1] Subcommittee on Health and Long-Term Care, House Select Committee on Aging, "Abuses in Guardianship of the Elderly and Infirm: A National Disgrace, a Briefing by The Chairman," 100th Cong., 1st Sess. 4 (committee print 1987).

[2] This study and the series of articles is reproduced in "Abuses in Guardianship of the Elderly and Infirm: A National Disgrace," a Report by The Chairman of the Subcommittee on Health and Long-Term Care of the House Select Committee on Aging, 100th Cong., 1st Sess. (committee print 1987).

To the knowledge of TCSG and the Subcommittee, the national standards proposed here and the Michigan standards from which they were derived are the first attempts to set forth a comprehensive statement of roles and responsibilities of guardianship service providers. The standards also address representative payeeship because this form of surrogate decisionmaking can have serious consequences to the individual, and most providers of guardianship services also provide representative payee services.

Given that these proposed standards are a first effort, it is fully anticipated that they will evolve substantially and be refined as they are tested in practice. They are, however, an important step in delineating, for providers, funders, and monitors of guardianship services, tangible and specific directives -- directives which not only guide guardians in carrying out their duties but which foster the use of less serious forms of intervention whenever appropriate to the needs of the individual.

While the standards have applicability for anyone providing guardianship services, they are directed specifically at guardianship "programs." A "program" is defined as an individual or organization that serves five (5) or more clients[3] and receives funding or compensation[4] for services provided. As more and more "programs" are developed to provide surrogate decisionmaking services, it is critical that standards of practice be established early in the developmental stage to ensure that such programs provide an extra measure of service and safeguards to clients.

Indeed, there is an urgent need for all states to assess what is occurring with respect to establishment of guardianship service programs within their jurisdiction, and to then adopt standards to guide their development so that programs provide not only high quality guardianship services, but also alternative services. The Subcommittee and TCSG are concerned that, in the absence of alternatives, programs that make guardianship services easily available could lead to increased use of inappropriate guardianship, resulting in the creation of unnecessary dependence and loss of autonomy among the frail elderly.

It is our hope that these standards will serve as a blueprint to work from, and will promote dialogue and timely action at the local, state, and national levels. Such action is needed throughout the country to assure that surrogate decisionmaking services are provided in a uniform, high quality manner which maximizes the potential of every individual for self-reliance and independence.

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[3] Users of these standards may, however, opt to define a "program" based on a different number of clients served.

[4] Nominal or token compensation or reimbursement for proper and necessary expenses does not place a guardian or representative payee, such as a family member or friend, within this definition of "program."

PROPOSED MODEL STANDARDS FOR PROGRAMS PROVIDING GUARDIANSHIP AND REPRESENTATIVE PAYEESHIP SERVICES TO ADULTS

I. PREFACE

As noted in the introduction to this report, while much has been written about the inadequacies and the misuse and overuse of the guardianship system, relatively little has been produced that goes beyond delineating problems to dealing in positive, concrete terms with issues of quality in the provision of guardianship services. Thus, The Center for Social Gerontology (TCSG) has revised and adapted its Michigan standards for national use, and is pleased to present them here on behalf of the Subcommittee on Housing and Consumer Interests of the House Select Committee on Aging.

The evolution of these national standards has been a lengthy and demanding process; and TCSG wishes to note its indebtedness to the many persons who gave generously of their knowledge and time throughout that process. The national standards could not have been produced without the diligent efforts of those who helped develop the Michigan standards; and the Michigan effort relied heavily on the wide-ranging experience and expertise of numerous individuals. Five versions of the Michigan standards were drafted, discussed, refined, and redrafted. Particular thanks are extended to the Technical Advisory Committee[1] members for their constant and careful guidance at each stage in the drafting process.

The Michigan project was undertaken jointly with the Michigan Office of Services to the Aging (OSA) and was funded by the U.S. Administration on Aging (AoA). TCSG wishes to express appreciation to OSA and AoA for their leadership and support. Special thanks are extended to OSA's director, Olivia Maynard, and two OSA staff, Mary James and Cherie Mollison. Finally, the authors express their deepest gratitude to their administrative assistant, Susan Herman, and computer specialist, Cathryn J. Dean, for their excellent assistance with the myriad details and innumerable drafts involved in producing the Michigan and national standards.

II. INTRODUCTORY COMMENTS ON THE PROPOSED MODEL STANDARDS

A. Adaptation of the Michigan Standards for National Use

A process similar to that followed in developing the Michigan standards was used to turn them into the more general national standards set forth here. These Proposed Model Standards have gone through several drafts, and have been reviewed and commented on by national experts in guardianship and protective services. TCSG adds its thanks to that already expressed by Congressman Bonker in the opening pages of this document, for the valuable comments and suggestions that were submitted.

While the Michigan standards were aimed at all guardians and representative payees including individual family members and friends, the national standards focus on practices of programs and individuals providing guardianship and representative payeeship services as a business or social service to five or more adult clients. Although family members and friends make up the largest segment of persons providing guardianship and representative payee services,[2] singly they do not have the potential to endanger the health, welfare, and financial stability of large numbers of frail and vulnerable individuals that professional service providers have. Furthermore, as these service providers often receive public funds, it is paramount that they be monitored to insure public monies are being expended for quality services.

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[1] Technical Advisory Committee Members: Robert Brown, University of Detroit School of Law; Mary Fales, Monroe Legal Services; Peggy Fournier, Ogemaw County Public Guardian; Dohn Hoyle, Washtenaw Association for Retarded Citizens; Deborah Mattison, Michigan Protection and Advocacy Service; George A. McCathney, Monroe Legal Services; Tom Miller, Kalamazoo County Guardian, Inc.; Ken Moore, Area Agency on Aging, Region 1-B; Honorable Joseph J. Pernick, Probate Judge, Wayne County Probate Court; Jim Poelstra, Kent County Department of Social Services; John Sherman-Jones, Alger County Department of Social Services; Douglas Slade, Probate Register, Ingham County Probate Court; Honorable Alexander T. Strange, II, Probate Judge, Clare-Gladwin Counties; Elizabeth C. Sullivan, Division of Gerontology Services, Harper Grace Hospitals; Dan Thompson, School of Social Work, Western Michigan University.

[2] The study in Michigan would suggest that 80% of guardians and representative payees are non-professionals. See Lauren Barritt Lisi and Penelope A. Hommel, Report on Survey of Programs Providing Guardianship and Representative Payee Services in the State of Michigan 1 (Ann Arbor, MI: The Center for Social Gerontology, 1987).

Because guardianship services are provided by a variety of agencies and individuals with a diverse range of funding sources, organizational structures and management models, and according to differing laws and regulations, not all standards provided here will be equally useful or applicable in all states.

Keeping in mind the variation in states' laws and circumstances, efforts have been made to make these standards both as specific as possible and general enough that they can easily be adapted for state-specific use. In addition, the standards attempt to strike a balance between giving guardians and representative payees the independence needed to effectuate goals appropriate to their clients' needs in accordance with particular circumstances, while at the same time assuring high quality service delivery to all wards and beneficiaries.

B. Implementation of the Standards

One important reason for focusing the national standards on professional service providers is that this allows compliance to be achieved through the agencies which fund them. The conditions of funding can include a requirement of compliance. Enforcement and monitoring of standards compliance by all guardians (including individual non-professional, single-ward guardians), on the other hand, may necessitate that states make substantial changes in legislation, regulation, and court rules. Such enforcement is also likely to require expanded resources. Similarly, implementation through funding sources allows for enforcement of the representative payee provisions of the standards. Because appointment, monitoring, and dismissal of payees is the province of the agency which administers the benefit payments, courts have no direct authority over payees for federal benefits. However, since most guardianship service programs also provide representative payee services, funding agencies may mandate compliance with the standards as a condition of funding.

This observation is not meant to discourage states from implementing standards or developing enforcement mechanisms for all guardians and representative payees by court rule or legislation. In fact, no single method for implementation is contemplated by the authors or the Subcommittee. Perhaps ultimately, state legislative changes accompanied by adequate appropriations may be the most effective way to implement such standards. It is judges operating under statute and court rule who have the ultimate power to demand high quality guardianship services. Similarly, government benefit agencies operating pursuant to statute and regulation have enforcement power over representative payees.

Revision of these national standards so that they are applicable to all guardians and representative payees -- not just professional service providers -- is a relatively easy task, as many provisions would apply to any guardian, whether a family member, friend, or organized program.[3] With the exception of some of the provisions in Standard 4, Standards 1 through 11 could generally be applied to all guardians and representative payees.

In the U.S. Congress, several bills were introduced in the 100th Congress and are expected to be reintroduced in the 101st. They would require states to implement legislation to protect the rights of allegedly incapacitated persons and persons already determined to be incapacitated. One bill, H.R. 5266 "National Guardianship Rights Act of 1988," was introduced by Congressmen Claude Pepper and Don Bonker, with a companion bill in the Senate by Senators John Glenn and Paul Simon. A bill was also introduced by Congresswoman Olympia Snowe. While the federal bills focus primarily on

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[3] In fact the Michigan Standards, upon which these standards are modeled, specifically indicated those standards which would apply to non-program guardians. These standards are available as a model to states wishing to modify the national standards.

procedural and due process protections related to establishing guardianships, they also begin to address concerns about the provision of guardianship services (e.g. training of guardians, qualifications of guardians).

If such legislation is adopted by Congress, all states would be required to examine their state laws to determine the extent to which changes are needed to bring those laws into compliance with federal requirements. This examination of state laws would provide the perfect opportunity for a discussion within each state of the need for guardianship performance standards. In the absence of federal requirements, measures for standards implementation should nonetheless be developed by all states.

C. The Proposed Model Standards Document

The standards document is comprised of three sections. It first defines terminology used in the standards. Attempts have been made to provide uniform terms to describe the variety of guardianship relations that may be created. Because terms vary from state to state and even within states, this section is crucial to an understanding of the standards. The use of jargon has been avoided to the extent possible. In some situations, however, where certain terms have specific meaning for certain groups (e.g. "normalization"), and meaningful substitute terms could not be found, they have been included. The second section of the document sets out overriding fundamental principles that should guide all decisionmaking by surrogates. And the third sets forth the standards themselves.

Although the standards themselves focus on the duties of guardians and representative payees after their authority has been imposed, an integral and crucial part of encouraging maximum self-reliance and independence is the continual need to explore and implement less restrictive alternatives to guardianship and representative payeeship where appropriate. The authors have tried to reflect this overriding duty throughout the standards. It should remain foremost in the minds of all persons who serve individuals facing possible state-imposed interventions.

For ease of reference, the most important language within the provisions of the standards has been highlighted with underlining. The standards document does not reflect any particular state statute. Provisions are based on a general understanding of guardianship laws around the country. Nonetheless, it is expected that there will be instances in which a particular provision does not fit within the practices and laws of a particular jurisdiction. It is hoped that the general intent of all provisions is clear so that those which do not fit a particular state situation can be modified accordingly.

III. BACKGROUND DISCUSSION OF KEY ELEMENTS AND PROVISIONS OF THE STANDARDS

This background discussion is presented to enhance understanding and appreciation of the meaning and intent of the standards and their underlying principles. It examines the considerations that went into formulating specific provisions of the standards. This examination includes, where appropriate, a discussion of the comments and suggestions of reviewers, the rationale for the current provision, and, where useful, examples or suggestions on the use or meaning of particular provisions. Not all standards provisions are examined below. Only those provisions that engendered some controversy or were particularly difficult to formulate are discussed.

A. Cornerstones of the Standards: Definitions and Underlying Philosophy

COMMENTS ON THE DEFINITIONS

To be able to read and interpret the standards accurately and to discuss their benefits and costs meaningfully, it is important to have a clear understanding of the meanings of terms used therein. The importance of the definition section becomes even greater in light of the fact that terms used to describe guardians and the guardianship process vary greatly among and within states. Similarly, terminology used to describe representative payees varies among agencies.

The definition section attempts to set forth uniform terms to describe the various surrogate decisionmaker relationships covered by the standards. In addition, the authors have tried to define important concepts -- e.g. "best interests," "least restrictive," "least intrusive," "normalization," "substituted judgment" -- which, although frequently cited, are not commonly or easily defined. Finally the definition section defines words which have special meaning within the context of the standards -- meaning which does not always coincide with the normal usage of the term.

Set out below is an examination of selected terms found in the definition section, including, where appropriate, a brief explanation about the derivation of the meaning adopted for use in the standards.

(1) "Best Interests" is a term which is commonly used when describing surrogate decisionmaking but which is seldom clearly defined. The definition adopted for the standards describes the goals of actions and decisions undertaken "in the best interests" of the ward or beneficiary. These goals -- focusing on the implementation of the least intrusive, most normalizing, and least restrictive course of action -- are to act as guideposts to surrogate decisionmakers, restricting the surrogate's discretion to do anything (s)he thinks is in the "best interests" of the ward or beneficiary. The definition also requires consideration of the ward's or beneficiary's desires. The definition makes it clear that a "best interests" criteria should only be applied in surrogate decisionmaking if reliable evidence of the ward's or beneficiary's views prior to appointment of the surrogate decisionmaker are not known -- i.e. if a substituted judgment standard cannot be used.

Some reviewers of the standards believe it is inappropriate to consider current desires of the ward or beneficiary when using a "best interests" test. They suggested that any consideration of the person's wishes demanded that decisions then be made pursuant to a substituted judgment standard. It is the position of the drafters that current desires of wards and beneficiaries have a place within both principles of decisionmaking. In the context of "substituted judgment," current desires of the ward or beneficiary are evidence of opinions and desires prior to appointment of the guardian or representative payee. Where such opinions or desires are known, surrogate decisions should attempt to effectuate these desires. In the context of "best interests," current desires are not evidence of prior wishes, but are instead just one factor among many that go toward determining what is in the best interests of the person. A decision contrary to current stated desires may have drastic adverse effects on the psychological or emotional well-being of the person, no matter what its beneficial physical effects may be.

It is important to note that although "best interests" and "substituted judgment" are theoretically discrete and different decisionmaking methods, it may be more appropriate to see them as opposite ends of a continuum. In the middle, there is a gray area where it may be difficult to distinguish between decisionmaking pursuant to a best interests test and decisionmaking based on a substituted judgment principle.

(4) "Facility" has been defined very broadly to encompass residential and institutional settings that limit to some degree the independence and autonomy of the resident. Specific settings meeting this criteria are enumerated. Generally such settings are subject to state licensure requirements. Because nomenclature varies greatly around the country, the list given here may be inappropriate within a particular state or may omit a setting that should be included. The list of facilities set out in this definition should be modified where necessary, to accurately describe settings that fit within the overall purpose of the definition.

(5) "Fiduciary" is a difficult term to define. The definition in this document is a very broad one derived from definitions found in Black's Law Dictionary.

(6) "Funder" is defined as any organization or agency (private or governmental) which funds guardianship or representative payeeship services. Increasingly, social service agencies, counties, area agencies on aging, courts, and other governmental and private entities are funding the provision of such services. Funding agencies have a duty to assure that services are being appropriately provided. The funder is given a potentially large role in implementing and monitoring compliance with these standards.

(7) "Guardian" is used very broadly in the standards. It includes any surrogate decisionmaker appointed by the court. It describes both the surrogate who makes personal care decisions and one who makes financial decisions for the ward, as well as someone who has been given authority to make both personal care and financial decisions. It encompasses surrogates with full and limited authority, and surrogates with temporary and long-range authority. Terms vary greatly from jurisdiction to jurisdiction and even within them. Other commonly used terms include "conservator" and "committee." Further delineation of the various kinds of guardianship relations is given in the definitions of "Guardian of the Estate," "Guardian of the Person," "Partial Guardian," "Plenary Guardian," "Stand-by Guardian," and "Temporary Guardian."

(11) "Least Intrusive" and **(12) "Least Restrictive"** describe principles of decisionmaking. Both terms stress the need to allow the ward as much freedom and autonomy as (s)he has capacity for, while still providing adequately for the needs of the ward. "Least intrusive" describes the need to avoid all unnecessary interference with freedoms, while "least restrictive" describes the need to place as few limits as possible on individual rights and personal freedoms.

(13) "Normalization" is a term of art which is familiar to professionals working with persons with developmental disabilities. The term is not as familiar to those working with older persons. Although attempts were made to avoid the use of jargon wherever possible, no meaningful substitute could be found for this term, and thus it has been included. In this instance, although the term is not commonly used in all disciplines, the principle is one that should be applied to all ward and beneficiary populations. It stresses the need to allow all persons the opportunity to engage in activities, and live in conditions, which are culturally and socially accepted as normal in mainstream society.

(14) "Objective Third Party" defines individuals to be consulted by programs in particular instances, as described by the standards. Requiring consultation with such individuals assures an extra measure of security to the ward when particularly serious decisions are being contemplated. The definition describes individuals who have no affiliation to the program which could influence their advice on the matter for which they are being consulted.

(17) "Program" defines the individual guardians and representative payees, the agencies, and organizations who are expected to follow the Model Standards set out in this document. It includes any person or organization that acts as surrogate decisionmaker for more than five (5) persons and receives monies for such services, other than reimbursement for out-of-pocket costs. The second half of the definition is meant to encompass volunteer programs, in which individual unpaid volunteers may serve fewer than five (5) persons but the agency that recruits, trains and monitors such volunteers has a total caseload of five (5) or more wards or beneficiaries.

The number of clients bringing a guardian or representative payee within the definition of program was set at five after receiving numerous comments on a preliminary draft in which the number was set at ten. Several reviewers believe that any individual or organization that serves more than two or three persons is really acting as a business and should put in place the procedures required by the standards. In light of their comments, the number was lowered from ten to five.

(19) "Representative Payee" is the term used in the standards to describe anyone assigned to receive and handle government benefits on behalf of another. Terms describing this surrogate relationship vary from one government agency to another. Other terms include "substitute payee" or "fiduciary."

(20) "Social Services" is defined here in light of a provision of the standards which prohibits providers of guardianship and representative payeeship services from also providing housing, medical, or social services. The intent of that provision is to avoid potential conflicts of interest which may adversely affect the services delivered to wards. Comments on the conflict of interest provision advised defining "social services." The crux of the matter is whether case management services are included within the definition of social

services and are therefore services which a guardianship or representative payeeship program is prohibited from rendering. Pursuant to the adopted definition, any social service which is provided as an alternative to guardianship is not a prohibited social service. This would include case management services, when and if they are provided, as an alternative to guardianship.

These standards require that programs investigate and, wherever possible, implement alternatives to guardianship. It would be contrary to this fundamental precept to forbid guardianship programs from providing alternatives to guardianship. Accordingly, those services which avoid the need for guardianship are exempted from the definition of social services. However, a word of caution here is necessary. Alternatives to guardianship may be less desirable than guardianship if they are not truly voluntary. Social service alternatives, such as case management, come with their own potential abuses and dangers if they are coercively or otherwise inappropriately implemented.

(22) "Stand-by Guardian" describes a guardian that is ready and waiting to step in, in the absence of the initially appointed guardian. Although not all state laws provide for such a guardian, use of a stand-by guardian can be helpful for handling emergencies and periodic absences in single staff programs.

(23) "Substituted Judgment" is the preferred principle of decisionmaking pursuant to these standards. Decisionmaking pursuant to a substituted judgment principle recognizes the ward's or beneficiary's inherent right to self-determination. It requires guardians and representative payees to honor, where known, the particular and even idiosyncratic wishes of the individual ward or beneficiary expressed prior to appointment of the guardian or representative payee. As noted in the discussion on "best interests," the current desires of the ward or beneficiary should also be considered as they may shed light on prior wishes.

(25) "Ward" describes anyone for whom a "guardian" has been appointed. Just as with the terms that describe the guardian, the terms used to describe the person for whom a guardian is appointed vary from jurisdiction to jurisdiction. Other terms include "incapacitated person," "incompetent person," "conservatee," and "protected person."

COMMENTS ON THE FUNDAMENTAL PRINCIPLES

The second section of the standards document sets down fundamental and overriding principles which should govern the behavior of all guardians and representative payees. Because it is not possible or even desirable to prescribe behavior of guardians and representative payees in all circumstances, the fundamental principles section attempts to state broad goals and philosophies to guide performance of their duties. These principles stress the importance of granting every individual the maximum autonomy which (s)he is capable of handling. These principles should remain constant in the minds of guardians and representative payees. The nine fundamental principles are briefly discussed below.

(1) Guardianship and representative payeeship programs are required to implement, provide, and actively seek out alternatives to guardianship where appropriate. This report emphasizes the importance of alternatives to guardianship. The use of appropriate alternatives can ensure persons a greater measure of self-determination than that allowed by use of guardianships. Many alternatives allow the person to choose the surrogate decisionmaker, to limit the scope and focus of his/her surrogate decisionmaking power and to determine when the power to make decisions will begin and/or end. In addition, in setting up alternatives the person often can provide insights and guidance into the manner and criteria by which they wish decisions to be made.

Many communities have guardianship programs but do not have any individual or organization that can provide alternative surrogate decisionmaking services. When persons in these communities find themselves in need of surrogate decisionmaking assistance, they will necessarily be placed under guardianship (or, at the least, representative payeeship) because they cannot do without some measure of assistance and no less restrictive alternative service is available. For this reason, it is crucial that communities begin to implement programs providing alternatives to guardianship. To ensure the promulgation of such programs, the drafters have put the onus on guardianship programs. If they cannot find appropriate alternative services in their community, they must strive to implement such services. It is the drafters' belief that such alternative services must go hand-in-hand with the provision of more restrictive guardianship services.

(2) The guardian or representative payee shall actively work toward the goal of limiting or terminating the surrogacy, encouraging the appropriate restoration, maintenance, or development of maximum self-reliance and independence in the person. This principle is intended to remind guardians and representative payees that the purpose of the guardianship or representative payeeship goes beyond maintenance. The goal should be restoration of independence or development of a person's maximum potential for independence. This principle complements the first principle in that it requires proactive efforts by the surrogate to work toward removing restrictions on independence. In many instances these efforts will lead to implementation of less restrictive alternatives.

Without such a philosophy there is the danger that guardianship and representative payeeship will become mechanisms for warehousing vulnerable persons. Neither mechanism should ever be viewed as the beginning of the end for the ward or beneficiary, or as a means to handle a troublesome individual. The danger of such warehousing increases where services are provided by programs. Family members or friends providing surrogate services generally have a personal interest in the welfare of the one individual for whom they are acting. This may not be the case when services are provided by programs. Program staff may have no personal relationship with clients; and, in many instances, program caseloads are large and staff have limited time and resources to devote to individual clients. These circumstances, in combination, may lead to pressures to provide minimal services necessary to maintain the status quo of the individual. Recognizing the dignity of the person and the right of every individual to determine his or her own future wherever possible, it is paramount that guardians and representative payees continually strive to better the lives of their clients by encouraging mechanisms or courses of action which lead, wherever possible, to an increase in or a return to independence.

(3) The guardian or representative payee shall engage in surrogate decision-making pursuant to the principle of substituted judgment or, in the absence of reliable evidence of the person's desires, pursuant to the best interests of the individual. This third fundamental principle describes preferred criteria for decisionmaking. It sets up a two-tier decisionmaking structure, allowing surrogate decisions to be based on best interests only if it has been determined that reliable evidence on which to base a substituted judgment decision does not exist. This decisionmaking system recognizes the uniqueness of each person and attempts to dignify that individuality by focusing on the volition of each client. The surrogate is required to make attempts to determine what the client's desires would have been in such a situation. Only where there is no reliable evidence of the client's prior views should decisions be made based on what social norms deem to be the best interests of the individual. The important role that current desires of the person play in both "best interests" and "substituted judgment" decisionmaking has previously been discussed. (See the discussion of "Best Interests.")

(4) The guardian shall maintain the person in the most normalized and least restrictive appropriate environment. The fourth principle guides guardians with respect to decisions about the ward's environmental circumstances. In keeping with the focus on maximizing independence and honoring individuality, the guardian is to make every effort to ensure that the environment allows the ward the maximum degree of freedom appropriate to the ward's needs and offers the ward culturally normative circumstances and opportunities.

(5) The guardian or representative payee shall not exceed the bounds of legally granted authority. The fifth principle clearly states that the authority of the guardian and representative payee is limited to only those duties which have expressly been assigned to them. Whatever rights and powers have not been delegated to the guardian or representative payee remain with the individual and are beyond the scope of the surrogate's authority.

The distinction between powers which remain with the individual and powers which have been delegated to the surrogate, although seemingly simple, may in practice frequently be hard to discern. This is especially true in those instances in which the surrogate decisionmaker has power over the finances of the individual. Power over financial affairs realistically puts power over personal affairs into a guardian's or representative payee's hands. Pursuant to this principle, however, the guardian or representative payee is prohibited from using solely financial decisionmaking authority to influence the handling of personal care. For example, a representative payee does not have the power to withhold money from the beneficiary until the beneficiary has found suitable housing or until the beneficiary agrees to follow a regimen of prescribed medication. The temptation to coerce behavior that the guardian or representative payee believes is in the best interests of the person must be resisted. If a ward or beneficiary persistently engages in activities which evidence the need for greater surrogate authority, that authority should be properly obtained, either with the consent of the individual through use of an alternative to guardianship, or through court or benefit agency appointment of a surrogate decisionmaker with the specific authority to handle the matters in question.

(6) All wards and beneficiaries shall be accorded equal procedural protections and safeguards. The sixth principle recognizes that statutes, regulations, case law, and court rules have created artificial distinctions in the treatment of persons, based on the categorization of their incapacitating disability. For example, in Michigan there are two statutes governing the imposition and duties of a guardian. One statute covers persons with developmental disabilities and the other statute covers all other incapacitated persons. As a result, the procedure for obtaining a guardian and the authority, duties, and limits of a guardian vary depending upon the categorization of the proposed ward's disability. This principle recognizes that the effect of the guardianship on the individual's freedoms and autonomy is the same, whether the individual is developmentally disabled, mentally ill, or elderly, and requires that all individuals, no matter what their diagnosis, be accorded equal treatment.

This principle is not intended to deny any person the procedural protections or safeguards provided under state or federal law. If the law provides greater procedural protections to one group than are provided by these standards to all wards and beneficiaries, these standards are not intended in any way to supersede that law. It is suggested, however, that this principle would call for an evaluation of such state or federal law to see if protections provided under that law should be extended by statute or through guardianship standards to all categories of wards and beneficiaries.

(7) All wards and beneficiaries shall be delivered services in keeping with the standards regardless of their financial status or ability to pay for such services. Several reviewers thought this was an unrealistic principle. They felt that the realities of limited funding would prohibit programs from being able to comply with such a principle. In response to this concern, it should be noted that this principle does not require that services to all clients be equal. Instead it requires that the services and provisions for decisionmaking mandated by the standards be provided to all clients equally, regardless of their ability to pay. It does not prohibit the provision of additional or more costly services, not required by this document, to a wealthier client.

Nonetheless, the reviewers have raised a valid issue. These standards require the provision of high quality, labor intensive services; and such services will not come cheap. Programs cannot meet the requirements of this principle, and the standards as a whole, if they do not receive adequate funding and support. Therefore, this principle is as much a mandate to funders of guardianship and representative payeeship services as it is to providers.

(8) A guardian or representative payee shall treat the ward or beneficiary with dignity and respect. This principle seems so simplistic as to be almost trite. Yet, it is clear that guardians and representative payees do not always observe it. Treating the ward or beneficiary with dignity and respect implies more than speaking to them politely. It also means that guardians and representative payees must value the feelings and the opinions of wards and beneficiaries and must seek to determine the same. They must respect the privacy of the ward or beneficiary to the maximum extent possible. They must make every effort to treat the ward or beneficiary with the same respect and consideration they would give to an individual who was not the subject of a guardianship or representative payeeship. Such treatment conveys and validates feelings of value and worth in the ward or beneficiary and serves to remind the surrogate of the inherent worth of each client.

(9) A guardian or representative payee shall keep confidential the affairs of the ward or beneficiary. The ninth and last principle recognizes the great deprivation of privacy that occurs upon appointment of a surrogate decisionmaker. The imposition of guardianship or representative payeeship necessarily reveals the individual's affairs to the surrogate decisionmaker and to the scrutiny of the agency making the appointment. To preserve the right of privacy of the individual as much as possible, the surrogate decisionmaker shall not reveal information about the individual or his/her circumstances unless such revelation fits within one of three specified exceptions.

The first exception recognizes that the affairs of the individual must necessarily be revealed to the agency or court which appointed the surrogate so that such agency or court can monitor the performance of the surrogate and can make future determinations as to the continuing need for the surrogacy. A second exception occurs where the client is capable of giving informed consent. In such a case, information may be released upon obtaining full and voluntary consent to the release from the client. For example, a client subject to a guardianship of the estate might give the guardian consent to release financial information for the purpose of qualifying for public housing.

The last and broadest exception allows for the release of information when such release is in the best interests of the ward. For example, a client who is subject to full guardianship may not be capable of giving knowing consent to the release of medical information to a treating physician. If such information is necessary to the treatment of the ward and such treatment is in the best interests of the ward, the guardian should release such information for that limited purpose. Because this exception is so broad, guardians and representative payees should be careful to keep in mind the need to balance the continual pressure to reveal information about clients to an unending host of individuals and agencies against the client's right to confidentiality. It goes without saying that this principle would prohibit idle chatter about client affairs with friends or family.

B. Background Discussion of Key Provisions of the Standards

The third section of the standards sets forth the specific provisions which describe the duties and obligations of a guardianship or representative payee "program." As noted above, "program" is defined as an individual or organization that receives funding or compensation for guardian or representative payee services provided to five (5) or more persons. Nominal or token compensation or reimbursement for proper and necessary expenses does not place a guardian or representative payee in the category of a program. More and more individuals and organizations are beginning to provide guardianship and representative payee services as a business. Because of the potentially grave effect poor or improper surrogate services could have on the many people served, these businesses must provide an extra measure of service and security to clients.

Background on some of the individual provisions of the standards is set out below.

Standard 1. Duties of the Guardian of the Person. The first provision discusses the duties of the guardian who is responsible for making personal care decisions for the individual. The standard lays out a broad range of possible duties the guardian may have. The entire standard, however, is prefaced with the cautionary phrase "[w]here the guardian . . . has been granted such authority by the court. . ." indicating that such duties are not to be undertaken unless the guardian has been given plenary authority over the

person or unless (s)he has been given the authority to undertake the particular duty at issue. A new section was added to Standard 1 [1(A)(6)] as a result of reviewer comments. This section recognizes that the guardian of the person may also have responsibility to handle limited funds of the ward. When the guardian of the person has such responsibility, Standard 1(A)(6) requires adherence to all the requirements of Standard 2, pertaining to the duties of the guardian of the estate.

Standard 2. Duties of the Guardian of the Estate. As in Standard 1, this standard is prefaced with the caution that listed duties can only be exercised where the guardian has been given the appropriate authority. Also, as a result of reviewer comments, a new section [2(A)(5)] was added to Standard 2. This provision requires the guardian of the estate to allow the ward to manage funds as is appropriate, in order to encourage and foster maximum independence in the ward.

Standard 3. Duties of the Representative Payee. The specifics of this provision engendered no comment. However, one reviewer suggested that it was awkward to handle both guardianship and representative payeeship standards in a single document. She noted that the two mechanisms are different and that guardianship/conservatorship standards should be higher than standards required of a representative payee.

The drafters agree that, ideally, separate standards should be promulgated for representative payees. However, given the fact that no standards currently exist for representative payees, the drafters believe it is important to develop and include provisions dealing with representative payees in this document. The power of the representative payee, although intended to be limited, in reality may be quite broad. If the representative payee manages benefits representing the bulk or all of the income of the person, the representative payee may effectively exert control over a wide range of the beneficiary's personal affairs and decisions. Control of an individual's money provides control over the individual. This made the drafters believe it was even more important to promulgate standards for representative payees. Perhaps, at some future time, a separate document concerning representative payeeships only will be developed.

As a final note, any confusion caused by handling both guardianship and representative payeeship standards in a single document may be outweighed by the convenience and ease of having to refer to only one document. Many surrogate service providers provide both guardianship and representative payee services. Having all standards in a single document may be more convenient, thereby promoting the use of the standards.

Standard 4. Avoidance of Conflict of Interest. This standard sets forth those activities or relationships that a program shall not undertake, in order to avoid a conflict of interest, or even the appearance of a conflict of interest. Because many of the provisions within this standard engendered heated debate, each provision is discussed separately.

Standard 4(A)(1) prohibits a program from providing housing, medical, or social services to a person if that program also provides guardianship or representative payee services to the individual. Provision by a single entity of both surrogate decisionmaking services and housing, medical, or social services raises several problems.

First, a surrogate decisionmaker who stands to benefit financially from services received by the ward or beneficiary may be influenced to provide such services even where they are not truly needed. The impetus to implement unnecessary services may exist even where the program does not receive payment from the client for services. This is because continued public funding for services provided free to clients often depends upon a program's ability to demonstrate the continuing or increasing need for such services. This subtle pressure upon service providers to generate clients may be enough to put them into a conflict situation if they also have responsibility for making decisions about services needed by wards or beneficiaries. Second, a surrogate decisionmaker will find it hard to advocate for needed improvements in services, if such services are being provided by the surrogate decisionmaking agency. For example, the operator of a board and care facility (e.g. adult foster care facility, residential care facility) who receives and dispenses the personal needs allowances for residents of the facility (for whom the operator also serves

as guardian or representative payee) may not object to the failure of beneficiaries to receive their personal needs allowance. A less extreme example would be the guardianship program which also provides homemaker services. That program may be unable to fully advocate for improvements in the delivery of homemaker services (e.g. strengthened regulations) because of their involvement in the provision of such services.

At the current time, it appears that many guardianship and representative payee programs provide additional services, namely social services, which would put them in violation of the provisions of this standard. To answer some of the concerns of these programs, the provision provides an exception to the prohibition. Where a program can demonstrate that strict application of this provision would cause a hardship to a ward or beneficiary -- e.g. there is only one agency capable of providing both services -- that program may receive a limited waiver to provide both services. Some of the reviewers, however, were concerned about the potentially huge loophole the waiver provision could create. In response to these concerns, a sentence has been added that requires the waiver-granting agency to design specific procedures for the granting of waivers. These procedures must require a showing of hardship to the ward or beneficiary before a waiver will be granted.

Because of local variations in surrogate service provision and in implementation and enforcement of standards, it was unnecessary to further define the procedures for granting of waivers. States that adopt their own version of standards should consider delineating further the procedure for granting waivers. If waivers become the rule rather than the exception, the local community or state should work to implement additional and separate programs to provide the services which are the cause of the potential conflict and for which the waivers are being granted. Repeated waiver granting should be seen as only a temporary measure.

Finally, many guardians who have reviewed the standards raised questions about the definition of social services. Specifically, they asked whether it was intended to preclude the provision of case management services. As noted in the discussion of definitions, social services, as defined herein, do not include alternatives to guardianship. It would be contrary to the fundamental principles to forbid guardianship programs from providing alternatives to guardianship. Accordingly, those services provided in an effort to avoid the need for guardianship are exempted from the definition of social services. In general, this would mean that guardianship and representative payee programs may also provide case management as an alternative service. It is important to note, however, that case management services are not a true alternative if they are not voluntarily accepted. Such services, because of the absence of court scrutiny, can potentially be more dangerous than guardianship services, if they are coercively and inappropriately imposed.

Standard 4(A)(2) prohibits a program providing formal advocacy services from serving as guardian or representative payee to any person. This provision raises concerns similar to those raised by Standard 4(A)(1). A formal advocacy program providing guardianship and representative payee services will find it difficult to challenge its actions as guardian or representative payee. The standard gives three examples of the kind of advocacy service which should not provide surrogate services: legal services providers, ombudsman programs, and Protection and Advocacy Services (i.e. for the mentally ill and the developmentally disabled). Reviewers suggested additional advocacy services such as associations for retarded citizens, mental health associations, alliances for the mentally ill, and organizations of retired persons which should also be included within the prohibition. After much debate, these additional organizations have not been included as examples of formal advocacy services.

As the term is used here, formal advocacy services are publicly-funded services which have as their primary purpose the protection of individual rights. The services named in this provision all provide specialized services which are not easily obtained from other service providers. The groups suggested by reviewers did not fit within this strict definition of formal advocacy groups. The intent of the prohibition against advocacy programs providing surrogate decisionmaking services is to leave open to vulnerable wards and beneficiaries the services of these specialized agencies. To interpret formal advocacy services too stringently is likely to rule out some of the best qualified guardianship and representative payee service providers. Because the guardianship and representative payee standards set out here require vigorous advocacy efforts, programs with expertise in advocacy should not automatically be excluded. However, where those programs offer specialized advocacy services which cannot easily or appropriately be delivered by another agency, the danger of closing off advocacy avenues for vulnerable wards and beneficiaries requires that such programs be prohibited from providing surrogate decisionmaking services.

Standard 4(A)(3) prohibits programs from acting as the petitioner in a guardianship proceeding, or serving as guardian *ad litem* or as court-appointed visitor or investigator in a guardianship proceeding. This conflict-of-interest provision prevents the guardianship program from being in a position to influence a guardianship hearing or its outcome. It is important to remember that these standards apply to surrogate decisionmaking programs, and therefore this provision would in no way prohibit a family member from filing a guardianship petition for a relative. This provision does not limit the prohibition against involvement in the appointment process to those cases in which the program will be appointed guardian. The drafters of the standards believe that a blanket prohibition is advisable in order to avoid any chance that a guardianship program might instigate or affect a petition and then subsequently be named as guardian.

A few reviewers objected to a prohibition on guardianship programs filing petitions for guardianship. They indicated that in some locales the guardianship program is the only entity available and willing to file petitions for some individuals. A reviewer from California indicated that in her state the conflict of interest issue was resolved by the requirement that a petition contain specific statements, from an agency other than the filing agency, about the need for guardianship. A reviewer in Michigan suggested that this provision was unnecessary because the judge hearing the petition should be capable of distinguishing appropriate from inappropriate petitions.

These comments notwithstanding, the prohibition has been retained. The drafters and the majority of reviewers believe that the prohibition provides one more very important safeguard against the possibility of improperly imposed guardianships. In addition, the authors' research indicates that most guardianship programs are extremely busy and have very high caseloads. This prohibition would force communities to consider and use an alternate service provider to petition for guardianship, thereby allowing guardianship programs to concentrate exclusively on providing services to their existing wards.

Standard 4(A)(4) prohibits commingling program funds or staff members' personal funds with the funds of a ward or beneficiary. As noted in the text, this provision does not prohibit consolidation of clients' funds in joint accounts. Several reviewers indicated that such commingling of client funds should be prohibited as the possibilities for abuse are too great. In this instance, the drafters have been convinced by guardianship service providers that the benefits of allowing consolidation outweigh the potential dangers. However, the provision also notes that such consolidation shall only be permitted where the program has personnel with expertise in accounting procedures. The program must keep accurate individual accountings of the funds in the joint account and must credit each client the interest that his/her funds have earned. Finally, the standards provide an extra safeguard by requiring annual audits of funds in the account for at least a random 20 percent of clients.

Standard 4(A)(6) prohibits a program or its staff from borrowing funds from, or lending funds to, a ward or beneficiary. In response to comments received from reviewers, the drafters added language to this provision to allow no-interest advances to clients made for the purpose of off-setting a short-term emergency situation. For example, occasionally clients' checks will fail to arrive when scheduled. In such cases, the program may make a no-interest advance to the client until the funds arrive. The provision also permits loans if approved by the court or the benefit-administering agency.

Standard 5. Rights of Wards and Beneficiaries. Pursuant to this standard, guardians and representative payees are required to inform clients of those rights which they still retain. The rights which all wards retain are enumerated in Standard 5(A)(1) - (8). Additional rights, which may depend on the scope of the power granted and upon the laws of the jurisdiction, are enumerated in Standard 5(A)(9) - (13). The provision currently requires the guardian to request guidance from the courts with respect to such additional rights. If this provision is adopted within a particular jurisdiction, it is suggested that the additional rights of wards in that jurisdiction be clearly specified in the standards document or compiled in a list for distribution by guardianship programs, rather than asking programs to consult with the judge in every case.

As a result of comments by reviewers, language has been added to Standard 5(A) and Standard 5(B) that would require guardians and representative payees to inform clients of their rights both orally and in writing. Notification of rights should occur even where it appears that clients are incapable of understanding the notification. In addition, the program is required to obtain the client's signature on a copy of the written rights document and to deliver that copy to the court or the agency administering benefits. The purpose of this language is to try to ensure that clients are truly and meaningfully notified of their rights. If the client is incapable of signing, a disinterested third party can sign indicating that (s)he witnessed the delivery of both an oral and written explanation of rights to the client. At least one reviewer stated that asking the client to sign such a document would be meaningless and would likely frighten the client. This is certainly an issue which should be considered when adopting or implementing these provisions. Nonetheless, the drafters have retained the provision for lack of a better safeguard to ensure clients are properly notified of their rights. If a jurisdiction has a system which can better ensure proper notification of their rights -- e.g. using court personnel to explain rights to wards -- the drafters would applaud the use of that system.

Standard 6. Initial Steps. This standard examines the activities which must be undertaken upon appointment. To deliver quality surrogate decisionmaking services, surrogates must have in-depth knowledge of their wards -- what forms of support they have; what support they need; what their values, desires and beliefs are; what financial resources they have; their health status; and so forth. Acquisition of this information requires the guardian to engage in factfinding and investigation, as detailed in Standard 6(A)(4) and (5).

Standard 6(A)(8) stresses the importance of drafting and following a client plan that outlines the goals for the guardianship or representative payeeship. This is valuable in that it encourages a goal-oriented rather than a maintenance approach to the surrogate's duties. As a result of reviewers' suggestions, this provision requires participation of clients in formulation of plans to the extent possible. The specific issues to be addressed by the client plan were suggested by reviewers and borrowed in part from the Model Guardianship and Conservatorship Statute, prepared by the Developmental Disabilities State Legislative Project of the American Bar Association Commission on the Mentally Disabled (1979) §§17(2)(a) - (b). These issues stress the use of least restrictive interventions, conditions and services, and the need to make plans suited to the unique situation of the ward or beneficiary. In order to ensure the plan is seriously devised and conscientiously followed, the provision calls for review of the initial client plan at the next scheduled review of cases and for submission of the plan to the court or benefit agency, as well as to other relevant parties. Submission of the plan to these agencies or persons allows for third party monitoring of efforts to implement the plan.

Standard 7. Personal Contact and Ongoing Responsibilities. This standard lays out the day-to-day, ongoing duties of the surrogate decisionmaker. Standard 7(A) reiterates the need to monitor the client plan set out in Standard 6(A)(8) and to make changes to that plan as required by changes in the client's circumstances. Standard 7(B) stresses the importance of cooperation between and among surrogate decisionmakers. The duties of guardian of the person, guardian of the estate, and representative payee are not always delegated to, and exercised by, the same individual or program. For example, a bank or law firm may act only as guardian of the estate. Duties of guardian of the person might be delegated to a family member or a local guardianship program. In order to ensure the needs of the ward are met, these two decisionmakers must work together. For example, the guardian of the person may need to ask the guardian of the estate for additional or extraordinary funds in an emergency situation. If these different surrogate decisionmakers cannot work cooperatively, the client may suffer. The need to work cooperatively, however, should not prohibit one surrogate decisionmaker from informally monitoring the work of another and, if necessary, reporting improper conduct to the court, benefit agency, funding source, or other appropriate monitoring or advocacy agency.

Standard 7(C) and Standard 7(D) discuss the visitation requirements of surrogate decisionmakers. Because surrogate decisionmakers have tremendous powers and are granted authority to determine important matters for another, it is crucial that they be fully apprised of the person's circumstances. To be so apprised requires regular contact with the person and others responsible for his/her care.

In trying to set a minimum standard of visitation, some reviewers noted the variety and uniqueness of each client's circumstances. In many instances the need for visitation may depend upon the power exercised by the surrogate (the greater the power, the more need for contact), the living situation of the client (clients in the community generally require more assistance than clients in supervised settings), the availability of family and other support systems, and the stability of the client's circumstances (health, functional abilities, finances, etc.). Some guardians indicated that it is inappropriate to set any visitation requirement; and that requiring prescribed visitation of all clients might limit the time available to visit clients with more pressing needs.

Guardians also raised practical problems with respect to visitation of clients who are very far away. In some situations, clients may be moved out of the county or even out of the state without a change in surrogate decisionmakers. In Michigan, for example, it is not unusual to have a public guardianship program with a client 300 miles away. In implementing visitation requirements, some thought must be devoted to the handling of visitation when clients are living at a great distance from program offices. In most circumstances, it would be best to have the court in the jurisdiction in which the client is located appoint a nearby surrogate.

Standard 7(C) requires that guardians of the person -- surrogate decisionmakers who may be asked to make such important decisions as what medical treatment a ward will receive or where the ward will live -- visit with wards at least monthly. Originally Standard 7(C) contained an alternative provision which stated: "Guardians of the person shall attempt to have meaningful visits with their wards no less than once a month, but shall visit at least once quarterly. If wards are not visited at least once monthly, the guardian shall have monthly telephone contact with the ward or some individual in personal contact with the ward." This alternative provision is viewed by many guardians and funders of guardianship services as more realistic given the large caseloads of many guardianship programs. All seemed to agree, however, that the preferred standard would be monthly visitation.

In an effort to set out an ideal standard of visitation, only the provision requiring monthly visitation is retained. Jurisdictions that cannot realistically expect guardianship service providers to meet a monthly visitation requirement may wish to temporarily adopt the alternative quarterly visitation provision. However, this should only be a provisional measure. If quality guardianship services are to be provided, programs must have the staff and resources to visit all wards for whom they serve as guardian of the person at least monthly. Without such frequent contact, the program cannot ensure wards that sufficiently informed decisions will be made on their behalf. It is important to note that this minimum should not become a maximum. Many wards may be in circumstances where their conditions are changing so rapidly that more frequent visitation is required.

Standard 7(C) also requires quarterly visitation for guardians of the estate and representative payees. Because these surrogate decisionmakers do not have the power to make the personal care decisions granted to the guardian of the person, the visitation requirement need not be as stringent. In general there was little opposition to the requirements of this provision. Again, however, it is worth noting that the guardian of the estate or the representative payee, through the power they exercise over money, may greatly affect the life of the client. Accordingly, this requirement should also be regarded as a minimum. If circumstances dictate more frequent visitation, such visitation should be undertaken.

Standard 7(D) describes the activities to be undertaken if visitation is to be meaningful. Some guardianship service providers objected to the term "meaningful visit." They felt that "meaningful visit" did not suggest the significant and serious nature of the contact described in this provision. After searching long and hard for a substitute term, the term "meaningful visit" has been retained. While "meaningful visit" may have unintended connotations to some, the drafters have no better alternative term. Others who subsequently adopt these standards may wish to give the matter further thought.

The only other comment on this provision suggested that meaningful visits did not have to be limited to visiting at the ward's current residence, and that guardians should be encouraged to take wards for outings appropriate to the ward's capabilities. While the drafters would encourage such personal interaction between the guardian and the ward, the visitation provision requires observation of the ward's circumstances and conferences with caregivers. In

order to comply with these requirements, the guardian must spend at least part of the visitation time at the ward's residence. Having done so, there is no reason that guardians should not be encouraged to spend additional time with wards outside the residence.

Standard 7(E) addresses the need to keep a written record of contacts with the client and with other care providers. This is necessary for many reasons. First, a program serving many clients cannot expect to remember the circumstances and the actions taken on behalf of individual clients. In order to ensure continuity and consistency in the services provided, the surrogate must keep a record of impressions, plans, actions taken, decisions made, etc. Second, if the program has a number of staff, the same staff person may not always handle the affairs of a particular client -- e.g. in an emergency, when regular staff is on vacation, when there is staff turnover, or when duties for client care are split among staff. Third, records of contact facilitate case review and reporting to the court.

Finally, Standard 7(F) reminds the surrogate of Fundamental Principle 2, requiring the surrogate to work toward maximizing the autonomy and independence of the person.

Standard 8. Ward's Living Situation. The guardian of the person has the authority to determine the residence of the ward. Decisions about where the ward will reside are among the most crucial guardianship decisions, in terms of the effect on the well-being of the ward. The provisions in Standard 8 stress the need to carefully assess and monitor the living situation of the ward. Criteria for assessing the living situation are set out in Standard 8(A). They focus much attention on quality of life (e.g. opportunities to exercise independence) and other non-physical aspects of the living situation.

Standard 8(B) requires that moves to a more restrictive environment only be made after considering the criteria in Standard 8(A) and after consultation with professionals actively involved in the care of the ward. In addition the provision strongly encourages the guardian to consult with an objective third party. "Objective third party" is defined in the definition section and in Standard 8(B) itself. Examples of possible "objective third parties" are given.

Standard 8(C) addresses decisions to move a ward into a more restrictive "facility." "Facility" is defined in the definitional section. Guardians are restricted from placing wards in settings which meet this definition without first getting the court's approval to do so. The manner in which this approval is obtained is not detailed in the standard. It could be a fairly informal procedure or it could be done in a formal hearing. The purpose of requiring court approval is not to give the court the power to make decisions about wards' placement, but instead to have a mechanism for ensuring that these most important decisions are made carefully and with full consideration of the criteria provided for in the standard. To this end, the guardian is required to make known to the court the recommendation(s) of the objective third party.

A very important caveat to this provision states that no guardian may "voluntarily" admit a ward to a facility for the inpatient treatment of persons with mental illness. The consent of the guardian is not the consent of the ward. A guardian is appointed because the person does not have the ability to consent. Guardianship proceedings should not be used as a backdoor to commitment. Accordingly, the procedures for involuntary commitment required by the law of the jurisdiction must be followed to admit the ward to such a facility.

Standard 9. Securing Medical Services and Authorizing Medical Treatment. These provisions contain guidelines for medical decisionmaking. Standards 9(A) and 9(B) set out general requirements for all medical situations. Preventive medical intervention is stressed. Standard 9(A) requires that the guardian actively promote the health of the ward. This is to be done, in part, by obtaining annual dental and medical exams for wards. Some reviewers pointed out that in many instances wards may be without the funds to pay for such exams. In those cases compliance with the standards will result in additional expense to the program. This requirement has been retained despite the likelihood of the additional expense that will result. The drafters believe that annual exams are important enough that resources must be found to allow such exams for all wards. A resourceful program may be able to identify physicians and dentists willing to provide *pro bono* (free) exams to clients who are unable to pay.

Standard 9(B) sets out general criteria for any medical decisionmaking. These criteria are listed in order of preference -- i.e. if the criteria in Standard 9(B)(1) are met, then the guardian has no need to examine other criteria listed later. In compliance with the fundamental principles, these criteria require observance of client wishes as expressed prior to appointment of the surrogate. Therefore, specific declarations of intent -- e.g. living wills -- are controlling in decisionmaking. If such specific intent is unascertainable, then the guardian is to rely on substituted judgement decisionmaking. Only where no evidence of prior wishes is available is the guardian to move to "best interests" decisionmaking. Additional factors to be considered in making a best interests decision are set out in Standard 9(B)(3).

Standards 9(C), 9(D), and 9(F) categorize various medical treatment decisions by order of seriousness. Different decisionmaking procedures are required by each category, unless the client has executed a living will or other declaration of intent which addresses the particular decision to be made. If state law requires the guardian to engage in a different decisionmaking procedure, such law overrides the requirements of these provisions. If a jurisdiction chooses to adopt these standards, it is expected that specific standards provisions made inapplicable by state law would be deleted. Standard 9(E) discusses emergency medical decisionmaking. Each of these provisions is discussed briefly below.

Standard 9(C) sets out those decisions which can be made upon the recommendation of one doctor and do not require a second opinion. These decisions involve routine medical and dental procedures and administration of minor medications.

Standard 9(D) sets out those decisions which are so serious that they cannot be made without substantiating opinions of two examining physicians.

Standard 9(F) sets out those decisions which require prior approval of the court. These are decisions which may advance the death of the ward or seriously affect the ward's fundamental right of privacy. A number of questions were raised by reviewers about this provision, and some reviewers believe that the court should not be involved in medical decisionmaking of this nature. The following arguments against this provision were advanced.

Reviewers opposing it argued that its adoption would have great financial and administrative costs to the guardian and to the courts, and that courts do not have the time or resources to make these decisions. To require the guardian to go to court would often mean long periods of waiting for a decision which may come too late to benefit the ward. They also indicated that requiring court approval of such decisions takes time away from other important and more appropriate affairs of both the guardian and the court. In addition they noted that courts do not have any expertise which makes them better decisionmakers than guardians; and the decision rendered by a judge may be highly arbitrary and may be influenced heavily by personal beliefs and values of the judge.

Opponents also argued that wards' interests are adversely affected by the requirement of court approval. Not only may the court's crowded docket prevent quick and satisfactory resolution, but the mere fact of having a court make the decision may be harmful. The principles upon which these standards are founded stress the importance of treating the ward as much like a person who is not subject to a guardianship as possible. Requiring that persons with guardians have their medical affairs decided in a court of law does not comport with this philosophy. What is normally an intensely private and personal decision is made into a public matter involving several parties.

This provision has been retained despite these very important objections. In response to the issues raised by the reviewers, the following thoughts are offered. First, this provision may indeed involve financial and administrative costs to both the court and the guardian. The drafters believe, however, that such costs cannot be avoided in light of the need to guarantee wards that these most serious and extraordinary decisions are not made lightly.

Second, the drafters agree that courts do not have expertise in making medical decisions. However, this provision does not ask the court to make the decision. Rather the court is asked to approve the decision made by the guardian. It is intended to be a check on the guardian -- i.e. to ensure the guardian has consulted with all necessary medical professionals, the ward, and, where appropriate, the ward's family or friends; and to ensure that the guardian is applying the correct criteria for decisionmaking. Because of this

limited role of the court, the drafters believe that court approval can be obtained without a large investment of time. The guardian must gather the information to be relayed to the court in any event if the decision is to be thoughtfully made. It is important to note that the types of decisons included under this provision -- e.g. use of experimental treatment -- will not likely be made in emergency situations so that courts will have time to render decisions. It is fully expected, however, that where a medical issue needs to be decided quickly, courts would act accordingly.

Third, the intrusiveness of a court hearing is acknowledged, but a guardianship is by its very nature an intrusive proceeding. The ward's affairs are necessarily subjected to scrutiny in the imposition of the guardianship. If we are going to continue to protect persons whom the court has determined are in need of protection, then the requirement of court approval for very serious medical interventions is a justified intrusion on the privacy of the ward. It should also be reiterated that these standards apply to guardianship programs. In requiring that only program guardians go to court for approval of such medical decisions, we are not interfering with the personal decisionmaking of family and friends who act as guardian.

Standard 9(E) requires that in emergency situations the guardian abide by provisions of Standard 9 to the extent there is time to do so. In no event, however, may the guardian make any decision with respect to emergency medical care without first consulting with the treating or attending physician.

Standard 10. Disposition of Property. This provision provides guidelines on the disposition of both real and personal property. It sets out decisionmaking criteria to guide the guardian in determining when such disposition is appropriate. Standard 10(C) requires that the guardian obtain court approval before disposing of real property of the ward. The harm that can often be done by inappropriately or prematurely selling a person's home is immeasurable. It is reasonable to assume that the ward will interpret such a sale as evidence that he/she will never return home and will see it as the last "nail in the coffin." Physical and psychological consequences may then cause the ward's fears to come true.

Standard 11. Death of a Ward or Beneficiary. This provision explains the activities to be undertaken upon the death of a client. Some of the provisions of this standard may go beyond statutory duties of the guardian -- e.g. making funeral arrrangements. The drafters believe, however, that where permitted by the court, guardians should nonetheless engage in this activity because there is often no better-suited person to make such arrangements.

Standard 12. Programmatic Requirements. This provision deals with the procedures and practices necessary to the operation of a quality guardianship or representative payee program.

Standard 12(A) requires that the program have sufficient staff to adequately carry out the duties required by these standards and by the laws and authority pursuant to which appointment was made. Reviewers were asked to comment on the advisability of including a minimum staff-to-client ratio to ensure that programs were adequately staffed. In addition, reviewers were asked to suggest such a ratio. Many reviewers approved of the notion of a ratio. They were unsure however what that ratio should be. Those reviewers that had ideas about numbers suggested ratios of 1 to 30, 1 to 35, and 1 to 50. Others suggested that the ratio should vary from program to program, or should vary in accordance with the complexity of the cases handled by a particular staff member. One reviewer suggested that in addition to having a staff-to-client ratio, no program office should be responsible for more than 500 clients.

Studies and anecdotal evidence would suggest that the majority of guardianship and representative payeeship programs have staff-to-client ratios well above the numbers suggested by reviewers. In those instances, a significantly lower staff-to-client ratio might protect overburdened staff. However, this decrease cannot occur without an increase in funding resources. One guardian, paid from client funds, noted that she must have at least a 50-ward caseload to "eke out a living." Yet as one reviewer noted "to do the job correctly, there must be a very low staff-to-client ratio. Whether programs can exist under these circumstances is an open question."

The issue of setting a caseload limit was also raised at a conference attended by guardians. Based on feedback from conference attendees as well as the comments of reviewers, the drafters have decided not to include a staff-to-client ratio. Conference participants argued that maximum caseload size necessarily varied, depending on a number of factors that often could not be predicted. These factors included many of the issues noted in the discussion of visitation requirements, for example:

-- the geography of the area being served (if clients are spread geographically, more time must be expended in visitation and consequently fewer clients can be served);

-- the number of clients in institutional placement as opposed to placement in the community (generally clients in the community require more assistance than clients in an institutional setting);

-- the stability of the caseload (a good deal of time is expended in the initial stages of case-handling);

-- the work that program staff does which is unrelated to particular guardianship cases (e.g. diverting cases from guardianship);

-- the power exercised by the surrogate (the greater the power, the more time must be expended on the case); and

-- the stability of clients' circumstances (the handling of clients with many problems requires a good deal of time).

Conferees also noted that a staff-to-client ratio may not necessarily protect overburdened guardians. The ratio could instead have a negative effect on the guardian's ability to deliver services by becoming a driving force in the system. Although one guardian may have the ability to handle 30 wards, another may only be able to handle 15. A staff-to-client ratio might be used to demand that the guardian handling 15 wards take on additional wards that he/she cannot serve adequately.

The removal of a staff-to-client ratio from these proposed model standards is not meant to preclude adoption of such a ratio in circumstances where the variables noted above are better known. For example, a program providing only guardianship of the person services to older persons living in the community in a particular city may be better able to determine what an appropriate staff-to-client ratio is for that program.

Standard 12 (B) requires that all staff having responsibility for client care and/or the handling of client finances undergo a criminal record check and a reference check. Surrogate decisionmakers are given the power to exercise great control over the person and the money of another. It is crucial that anyone given such power be trustworthy, responsible, and honest. This provision forbids a program from hiring or retaining staff who have been convicted of a crime evidencing reckless or intentional disregard for the property or person of another. The standard of "reckless or intentional disregard for the property or person of another" is used in lieu of a category of crime -- e.g. a felony. The crimes within a particular category vary from jurisdiction to jurisdiction. In addition, not all crimes within a particular category are of a nature which evidences bad character. Nonetheless, the standard of "reckless or intentional disregard for the person or property of another" is not without its own problems. One reviewer commented on the broad nature of this standard, noting that it could be argued that a guardian convicted of speeding has committed a crime evidencing "reckless or intentional disregard for the person or property of another." Programs or jurisdictions adopting these Model Standards may wish to further define Standard 12(B).

Standard 12(C) requires programs to implement alternatives to guardianship where such alternatives are not currently available in the community. The reasons for such a provision have already been detailed in the discussion to Fundamental Principle 1. At the suggestion of a reviewer, this provision also requires that the program engage in activities to educate the community on the appropriate use of alternatives and the risks and advantages of each, as alternatives to guardianship are not without their own dangers. The provision also lists the alternatives that a program must implement if they are not already available in the community.

Standard 12(D) addresses training requirements for professional staff -- i.e. staff directly involved in the provision of guardianship services. This

provision defines staff to include both paid staff and volunteers. As one reviewer aptly noted, volunteers require a lot of staff time if they are to be effective. Their services are not without cost. Unless the program is willing to commit staff to recruiting, training, monitoring and supporting volunteers, it is probably best to use volunteers only in the performance of discrete tasks such as clerical help in the office, acting as a friendly visitor to clients, or helping clients with transportation needs. If volunteers are used in that manner, they will not require the full training set out in these standards.

This provision sets out curricula for initial training of surrogates and requires that such training be at least 30 hours in length. Additional annual training must be at least 8 hours (a full day) in length. The draft of standards sent to reviewers had a requirement of 20 hours of orientation training and 15 hours of continuing education. Reviewers suggested that 20 hours of orientation training was not sufficient. The current 30 hour/8 hour requirement was set after examining training and education requirements of other professions. The 8 hour continuing education requirement is not to be interpreted as the ideal for continuing education. It is considered to be the minimum that should be expected of surrogate decisionmakers, taking into account the pressures of their work.

Standard 12 (l) is largely the product of reviewer suggestions. In order to guarantee clients quality service, staff must have the ability to quickly access information on each client served by the program. This information allows staff to fill in for absent co-workers. It allows for effective review of cases by both staff and court, and it allows for a smooth transition if a staff worker leaves the program. Not only must all files be easily accessible, but the information within files must be kept in an orderly and pre-arranged location.

Standard 13. Fees. This provision attempts to ensure that all fees charged by the guardian or representative payee are reasonable. This provision sets a limit on the amount of fees which the surrogate can take and sets out criteria for determining when such fees may be taken. In general, fees may not be taken if the client's income is at or below the current federal poverty level. The provision requires that all fees be reasonable and be approved by the court or agency which appointed the guardian or representative payee. Fees also may not be taken if to do so will reduce the client's personal needs allowance permitted under certain benefit programs. In some jurisdictions guardians can take fees from Medicaid-eligible clients whose total income goes to payment for their care. The client's patient-pay amount is reduced by the amount of the guardianship fee, and Medicaid picks up a greater share of the reimbursement. The client is therefore left in no worse position because, with or without payment of the guardianship fee, the client only has discretionary income in the amount of the currently mandated personal needs allowance.

Several guardians have criticized the use of the federal poverty level income guideline to determine when fees may be taken. They have argued that wards can have incomes below the federal poverty level and nonetheless be accruing significant savings. If the ward has savings, these guardians believe they should be allowed to use them to cover their costs in providing services. In addition, guardians have noted that wards' resources and assets should be considered in deciding whether a fee can be collected. In spite of these suggestions, the drafters have decided to stay with the income test; and any savings of clients with incomes at or below the poverty level should be used to meet their current or future needs. Even clients with fixed expenses may need or want to buy personal items. Similarly, if proceeds from the sale of resources such as houses, cars, stocks and bonds, etc., can be used to pay surrogate fees, the surrogate may be influenced to dispose of such items. Putting surrogates in such a conflict of interest could easily lead to abuses. The drafters recognize that additional problems of using a strict income standard will likely reveal themselves as the standards are implemented. Further consideration of the matter should be made by jurisdictions or programs that adopt the standards.

This provision also limits the fees surrogates may collect to 5 percent of a client's income. This limit applies to the rendition of ordinary services. If the surrogate renders extraordinary services -- e.g. selling a house or other large property -- the surrogate should petition the appointing agency for guidance on the fee for such service. The primary issue in drafting this part was not what percentage the limit should be, but whether any limit should be set. It has been argued that a ceiling on fees will become a floor, and all surrogates will expect to receive 5 percent of the client's income, no matter how minor their services and no matter how large 5 percent may be. Nonetheless, upon the recommendations of reviewers, the 5 percent cap has been maintained.

Information available to the drafters indicates that programs have an endless variety of ways to determine fees. Some charge an hourly rate; some charge a flat fee; and some take a percentage of the client's income. Some collect fees at the end of the year; others take a fee every month or every quarter. The 5 percent limit is not meant to force programs into any particular method of calculating or taking fees. Programs should continue whatever method they have determined to be reasonable, provided that no ordinary fee ever exceeds 5 percent of the client's income.

At one time the drafters considered inclusion of a requirement that programs serve a minimum percentage of clients at no cost to the client. The provision was to be aimed at publicly-funded programs. Because this provision would only have further burdened laudable publicly-funded programs while allowing privately-funded programs to turn away poor clients, this requirement has been dropped. Its consequences on both publicly-funded and proprietary programs is difficult to predict. The drafters did not want to recommend such a policy without further study of its effects. In place of the contemplated provision, "programs are encouraged to provide *pro bono* services to indigent clients."

Standard 14. Review of Cases. This standard focuses on review of individual cases handled by a program as opposed to a review of the program itself. Program review is addressed in Standard 15. Standard 14(A) addresses the frequency, method, and criteria for case review by staff. Reviewers were asked to comment on the requirement that staff engage in case review at least monthly. All reviewers that commented approved of the monthly requirement. The monthly review needs to include only a sampling of cases. However, every case must be reviewed at least every 6 months. If staff cannot review all cases every six months using a monthly system, reviews may have to be done more frequently. In fact, the drafters would suggest that the monthly review period is a minimum and that programs interested in providing quality services should have more frequent reviews.

Review is required even where the program is staffed by only one person. The single staff program is required to review cases with an objective third party, a representative of the funder, or a community advisory committee. When review is conducted by, or with the assistance of, persons who are not program staff, this provision requires that identifying information on any documents be masked to protect the confidentiality of clients. Given the logistical and practical problems of getting together with the non-program reviewer, case reviews for a single staff program need occur only quarterly.

Standard 14(B) requires that a program allow a review of a sampling of cases by a committee of objective third party reviewers at least every 6 months. This committee could consist of legal services attorneys, social workers, families of persons subject to surrogate decisionmaking, former clients of the program, doctors, nurses, and other persons who have an interest in, or an understanding of, the issues involved in the provision of such services. It is hoped that such individuals would be willing to volunteer their time to such an endeavor and that therefore the cost would be minimal. In all cases of outside review, the provision calls for masking client identifying information to protect client confidentiality. At the suggestion of a reviewer, this provision requires the program to invite court personnel to sit on the committee. The program must also invite court staff to review on their own all, or a sampling of, program guardianship cases annually.

One reviewer suggested that the filing of an annual report with the court might make outside review unnecessary. The drafters disagree. First, studies indicate that courts often do not have the time or resources to monitor the filing of reports or to adequately evaluate reports which are filed. Secondly, the review contemplated by this provision is a much more in-depth review than that which can be provided by the court in most circumstances.

Standard 15. Review of Program. This provision requires an annual review of the program and sets out the criteria for that review. The individual(s) or organization which performs the review is left open, provided such individual(s) or organization is not affiliated with the program. The standard provides suggestions on possible reviewers. A jurisdiction adopting this provision may wish to specify a reviewing individual or agency. Some jurisdictions are currently contemplating the creation of a separate board to oversee and monitor the provision of guardianship services. If such a scheme were in place, the board might be able to assume the function of annually reviewing programs. Such a scheme has obvious benefits but will probably be somewhat costly, even if board members volunteer their time. As in the case with Standard 14, the provisions of Standard 15 address issues of confidentiality that arise in program review.

DEFINITIONS

As used, unless the context requires otherwise:

(1) **"Best Interests"** means that course of action which, in the absence of reliable evidence of the ward's or beneficiary's views prior to appointment of the surrogate decisionmaker, is the least intrusive, most normalizing, and least restrictive course of action possible given the needs of the individual ward or beneficiary. In considering the needs of the ward or beneficiary, due weight shall be given to the desires and objectives of the ward or beneficiary.

(2) **"Beneficiary"** means a recipient of government benefits for whom a representative payee has been appointed.

(3) **"Client"** means a person for whom a program has been appointed guardian or representative payee.

(4) **"Facility"** means an adult foster care facility, a congregate home, a convalescent home, a home for the aged, an institution or community residential program, a long term care unit of a hospital, a mental hospital, a nursing home providing intermediate and/or skilled care, a psychiatric hospital or psychiatric unit, a regional center, or any similar facility which is licensed by the state.

(5) **"Fiduciary"** means an individual, agency or organization that has agreed to undertake for another a special obligation of trust and confidence, having the duty to act primarily for another's benefit and subject to the standard of care imposed by law or contract.

(6) **"Funder"** means an agency, organization, or governmental unit contracting with or reimbursing a program for its services as guardian or representative payee.

(7) **"Guardian"** means an individual or organization named by order of the court to exercise any or all powers and rights over the person and/or the estate of an individual.

(8) **"Guardian of the Estate"** means a guardian who possesses any or all powers and rights with regard to the property of the individual.

(9) **"Guardian of the Person"** means a guardian who possesses any or all powers and rights with regard to the personal affairs of the individual.

(10) **"Interested Person"** means an adult relative or friend of the guardian or beneficiary, or an official or representative of a public or private agency, corporation, or association concerned with the person's welfare.

(11) **"Least Intrusive"** means a mechanism, course of action, or situation which allows the ward or beneficiary the greatest opportunity for autonomy with a minimum of intervention.

(12) **"Least Restrictive"** means a mechanism, course of action, or environment which allows the ward or beneficiary to live, learn, and work in a setting which places as few limits as possible on the ward's or beneficiary's rights and personal freedoms and is appropriate to meet the needs of the ward or beneficiary.

(13) **"Normalization"** means making available to wards or beneficiaries the patterns and conditions of everyday life which are valued by society and which are as close as possible to the normal or usual patterns of the mainstream society.

(14) **"Objective Third Party"** means any individual, agency or organization which has no interest, financial or otherwise, in the resulting actions or services undertaken pursuant to a particular guardian's or representative payee's decision, and is not involved in the day-to-day delivery of services to the ward or the operation of the program as a whole.

(15) **"Partial Guardian"** means a guardian who possesses fewer than all of the legal rights and powers of a plenary guardian.

(16) **"Plenary Guardian"** means a guardian who possesses the legal rights and powers of a full guardian of the person, or of the estate, or both.

(17) **"Program"** means an individual, agency, or organization that provides guardianship or representative payee services to five (5) or more individuals and receives funding or compensation, other than reimbursement for out-of-pocket costs incurred in providing services, or acts at the direction of an entity that receives funding or compensation for services provided as a guardian and/or a representative payee.

(18) **"Property"** means both real and personal, tangible and intangible, and includes anything that may be the subject of ownership.

(19) **"Representative Payee"** means an individual, agency, or organization named by a governmental agency to receive government benefits on behalf of, and for the benefit of, the beneficiary entitled to such benefits.

(20) **"Social Services"** means services provided to meet social needs. For purposes of this document it does not include services which are generally used to divert individuals from guardianship. The "alternative services" which are exempt from this definition include power of attorney services, trust arrangements, money management services, representative payeeships, and case management services.

(21) **"Staff"** means paid and volunteer personnel.

(22) **"Stand-By Guardian"** means a person, agency or organization whose appointment as guardian shall become effective without further proceedings immediately upon the death, incapacity, resignation, or temporary absence or unavailability of the initially appointed guardian.

(23) **"Substituted Judgment"** means the principle of decisionmaking which requires implementation of the course of action which comports with the individual ward's or beneficiary's known wishes expressed prior to the appointment of the guardian or representative payee, provided the individual was once capable of developing views relevant to the matter at issue and reliable evidence of these views remains. Current opinions and desires of the ward or beneficiary shall be examined and are relevant to a determination of the ward's or beneficiary's views prior to appointment of the guardian or representative payee.

(24) **"Temporary Guardian"** means a guardian whose authority is temporary.

(25) **"Ward"** means a person for whom a guardian has been appointed.

FUNDAMENTAL PRINCIPLES

The standards set out in this document are based on several fundamental and overriding principles. These principles shall be observed by each guardian or representative payee and shall be considered by the guardian or representative payee when implementing and applying the standards set out in this document. These principles are:

PRINCIPLE 1

Guardianship and representative payeeship programs are required to implement, provide and actively seek out alternatives to guardianship where appropriate. Guardians should always be searching for ways to use less restrictive interventions to ensure that guardianship is only utilized where it is truly needed. To foster the use and growth of alternative services, guardianship programs should be required to provide such services in addition to providing guardianship services. Alternative services should include not only representative payee services but durable power of attorney arrangements, trust arrangements, money management services, and case management services.

PRINCIPLE 2

A guardian shall actively work toward the goal of limiting or terminating the guardianship. A representative payee shall actively work toward dissolution of the representative payeeship. To this end, a guardian or representative payee shall encourage the ward or beneficiary in the appropriate restoration, maintenance, or development of maximum self-reliance and independence. The purpose of the guardianship or representative payeeship is restoration, maintenance or development of independence and capacity, wherever feasible. Guardianship and representative payeeship should not be viewed as enduring for life or as a means to handle a troublesome individual.

PRINCIPLE 3

A guardian or representative payee shall actively pursue that course(s) of action which comports with the principle of substituted judgment. Where reliable evidence of the ward's or beneficiary's views prior to appointment of the guardian or representative payee does not exist, a guardian or representative payee shall actively pursue the best interests of the ward or beneficiary, although these interests may conflict with the interests of the community, neighbors, caretakers, families, and other third parties. In pursuing the best interests of the ward or beneficiary, the guardian or representative payee shall attempt to effectuate the desires and objectives of the ward or beneficiary with respect to all matters, unless such desires or objectives are clearly not in the best interests of the ward or beneficiary. The focus of these standards is on honoring the client's volition as much as possible. Even where volition is no longer clear, every attempt should be made to determine what the client's desires would have been in such a situation. Only where absolutely no evidence of volition exists should the client be presumed to have wanted what social norms deem is in the best interests of the individual.

PRINCIPLE 4

Where a guardian has such authority, a guardian shall maintain the ward or, if necessary, move the ward to the most normalized, and least restrictive, appropriate environment that manifests opportunity for independence and autonomy. Not only should the guardian make every effort to assist in decisionmaking in the least restrictive manner, but in addition, the guardian should make every effort to ensure that the environment in which the ward lives, works, and engages in recreational activities is as free and culturally normative as possible.

PRINCIPLE 5

A guardian or representative payee shall not exceed the bounds of his/her authority as described by the court and/or the laws and regulations under which he/she is appointed. Whatever rights and powers have not been delegated to the guardian or representative payee remain with the individual. This distinction may seem simple but in practice a guardian or representative payee may have trouble leaving decisions, over which the guardian or representative payee has been granted no authority, to the ward or beneficiary when the guardian or representative payee feels the ward or beneficiary is not making the correct decisions. This is especially true in those instances in which the surrogate decisionmaker has power over the finances of the individual. Pursuant to this principle, a representative payee does not have the power to withhold money from the beneficiary until the beneficiary agrees to remain in suitable housing or until the beneficiary agrees to follow a regimen of prescribed medication.

PRINCIPLE 6

All wards and beneficiaries, whether elderly, developmentally disabled, mentally ill, or subject to some other categorization, shall be accorded equal

procedural protections and safeguards. The standards set out in this document attempt to avoid all artificial distinctions which may have been created by statute. In some states there is more than one statute governing the imposition of guardianship. The procedure for obtaining a guardian and the authority and duties of the guardian will vary depending upon the categorization of the proposed ward's disability – i.e. whether the individual is developmentally disabled, mentally ill, or an older person. These standards require like treatment of all individuals subject to similarly restrictive state interventions.

PRINCIPLE 7

All wards and beneficiaries shall be delivered services in keeping with the standards set out in this document, no matter what their financial status or ability to pay for such services. This does not mean that an indigent client must be provided with additional or more costly services not required by this document (e.g. a live-in maid rather than chore services, transportation by taxi rather than by bus, etc.). This principle requires that the services and requirements of decisionmaking mandated by this document be provided to all clients -- whatever their financial status -- who are served by programs coming under the provisions of this document. For example, all clients are entitled to second medical opinions pursuant to Standard 9(D) regardless of their ability to pay for such consultation. This principle is meaningless if programs do not have adequate resources to provide quality services to all clients. This principle is as much a mandate to funders of guardianship and representative payee services as it is to providers.

PRINCIPLE 8

A guardian or representative payee shall treat the ward or beneficiary with dignity and respect.

PRINCIPLE 9

A guardian or representative payee shall keep confidential the affairs of the ward or beneficiary, except: (1) for purposes of reporting to the court or the agency responsible for administering the benefits which are the subject of a representative payeeship; (2) when it is necessary to disclose such information for the best interests of the ward or beneficiary; or (3) when the ward or beneficiary, if capable, has given his/her informed consent to the disclosure of such information. The imposition of a guardianship or representative payeeship automatically reveals the individual's affairs to the surrogate decisionmaker and to the scrutiny of the agency appointing the surrogate decisionmaker. To preserve the right of privacy of the individual as much as possible, the surrogate decisionmaker must not reveal information about the individual or his/her circumstances unless such revelation is necessary to the well-being of the individual.

STANDARDS PROVISIONS

STANDARD 1. DUTIES OF THE GUARDIAN OF THE PERSON

1(A) If the guardian of the person has been granted such authority by the court, the guardian shall have the following duties and obligations to the ward:

(1) To see that the ward is appropriately housed. Performance of this duty shall involve consideration and compliance with the provisions of Standard 8. Proper performance of this duty requires the guardian to have frequent and meaningful visits with the ward pursuant to the provisions of Standard 7.

(2) To ensure that provision is made for the support, care, comfort, health, and maintenance of the ward. This includes the duty to make certain that the ward has applied for any financial, health

care, or other public or private benefits for which (s)he may be eligible. To this end, the guardian has the duty to become knowledgeable of, or seek out the assistance of, persons knowledgeable of existing services and legal entitlements to which the ward may be eligible. The guardian also has the duty to ensure the availability of someone, either the guardian himself/herself or another person, who has the knowledge and the ability to pursue the application and appeals procedures, including administrative and judicial procedures, necessary to obtain the entitlements.

(3) To make reasonable efforts to secure for the ward medical, psychological and social services, training, education, and social and vocational opportunities that are appropriate and that will maximize the ward's potential for self-reliance and independence.

(4) To keep confidential the affairs of the ward, except when it is necessary to disclose such affairs for the best interests of the ward.

(5) To file with the court all reports required pursuant to state statute, regulations, court rule, or the particular court pursuant to whose authority the guardian has been appointed.

(6) To the extent that the guardian of the person has been authorized by the court to manage the ward's property, the guardian shall adhere to the requirements of Standard 2.

(7) To carry out all other duties required by state statute, regulations, court rule, or the particular court pursuant to whose authority the guardian has been appointed.

STANDARD 2. DUTIES OF THE GUARDIAN OF THE ESTATE

2(A) The guardian of the estate shall have the duty to manage the ward's property to the extent authorized by the court and by statute, court rule, or regulation. In carrying out this duty, the guardian of the estate shall maintain the ward's lifestyle to the extent possible. If the guardian has the appropriate authority, this responsibility entails the obligation to:

(1) Act as the fiduciary of the ward, performing duties responsibly and honestly for the benefit only of the ward (and where appropriate, for the support of the ward's dependents), pursuant to the confidence and faith with which the guardian has been entrusted.

(2) To keep confidential the affairs of the ward, except when it is necessary to disclose such affairs for the best interests of the ward.

(3) To keep accurate records of all payments, receipts, and financial transactions undertaken on behalf of the ward.

(4) To ensure that all goods and services purchased on behalf of the ward are properly delivered and rendered.

(5) To allow the ward the opportunity to manage funds as appropriate. Many wards are capable of managing limited spending money. Wherever possible wards should be afforded this opportunity. Even if wards are prone to lose money, providing them with small amounts of cash -- e.g. $5 or $10 -- may be beneficial in promoting feelings of independence.

(6) To post and maintain a bond sufficient for the protection of the ward's estate.

(7) To comply with all requirements of the court including, but not limited to:

(a) the duty to file an inventory of the ward's assets;

(b) the duty to file accountings and other reports as required by the court.

(8) To carry out all other duties and obligations required by state statute, regulation, court rule, or the particular court pursuant to whose authority the guardian has been appointed. This may include the duty to:

(a) apply the ward's income, principal and other resources for the comfort and support of the ward and the ward's dependents;

(b) prosecute or defend against legal actions in any jurisdiction for the protection of the financial resources of the ward;

(c) perform contracts entered into by the ward before the onset of the ward's disability;

(d) when authorized by the court, execute and deliver any bill of sale, deed, or other instrument;

(e) settle, contest, or release claims against the ward;

(f) pay taxes and other reasonable expenses incurred on behalf of the ward;

(g) invest funds of the ward, as would a prudent person managing his or her own financial resources, for the ward's future needs. Prudent investments include deposits in an interest or dividend bearing account in a bank or trust company, or in a savings and loan association if federally insured, or otherwise insured in accordance with state law requirements and United States obligations of which both the principal and interest are guaranteed unconditionally by the United States.

STANDARD 3. DUTIES OF THE REPRESENTATIVE PAYEE[4]

3(A) The representative payee has the duty to receive and manage benefit payments on behalf of the beneficiary. This responsibility entails the obligation to:

(1) Act as the fiduciary of the beneficiary with respect to those benefit payments which the payee has been appointed to manage, performing duties responsibly and honestly for the benefit of the beneficiary, pursuant to the confidence and faith with which the payee has been entrusted.

(2) To keep confidential the affairs of the beneficiary, except when it is necessary to disclose such affairs for the best interests of the beneficiary.

(3) Spend payments for the benefit of the beneficiary. Payments shall be spent for the following purposes and in the priority listed:

(a) for the current maintenance of the beneficiary. Current maintenance includes costs incurred in obtaining food, shelter, clothing, medical care, and personal comfort items;

(b) for the current maintenance of the beneficiary's legal dependents;

(c) if the expenses in (a) and (b) above have been met, to cover past debts.

[4] In general, provisions in this document which pertain to the duties of representative payees can only be enforced by the agency responsible for payment of benefits and appointment of the payee. However an alternative method of ensuring compliance is possible where payee services are provided by a program funded by some source other than the ward's or beneficiary's estate. In those instances, the funders of such programs can require compliance with the representative payee provisions of this document as a condition of continued funding.

(4) After paying expenses listed in (3) above, invest, as would a prudent person managing his or her own financial resources, those funds remaining for the beneficiary's future needs. Prudent investments include deposits in an interest or dividend bearing account in a bank or trust company, or in a savings and loan association if federally insured, or otherwise insured in accordance with state law requirements and United States obligations for which both the principal and interest are guaranteed unconditionally by the United States.

(5) Ensure that all goods and services purchased on behalf of the ward are properly delivered and rendered.

(6) File accountings and other reports as required or requested by the agency administering the benefits.

(7) Promptly notify the agency responsible for administering the benefits on the death of the beneficiary, or any other change in the beneficiary's circumstances which may affect his or her entitlement to the benefits.

(8) Keep accurate records of payments, receipts, and financial transactions undertaken on behalf of the beneficiary.

(9) Carry out all other duties and obligations required by the agency administering the benefits.

STANDARD 4. AVOIDANCE OF CONFLICT OF INTEREST

4(A) A guardian or representative payee shall avoid all conflicts of interest and even the appearance of a conflict of interest. An appearance of a conflict of interest arises where the guardian or representative payee has a personal or agency interest which has the potential to adversely affect the interests of the ward or beneficiary. Specifically:

(1) A program shall not provide housing, medical or social services to an individual if the program is also acting as guardian or representative payee for that individual. The program's duty is to coordinate and ensure the provision of all necessary services to the ward or beneficiary rather than to provide those services directly. To insure that the guardian or representative payee remains free to challenge inappropriate or poorly delivered services and to advocate vigorously on behalf of the ward or beneficiary, the guardian or representative payee should be independent from all service providers. As defined in this document, social services does not include alternative services that are used to divert individuals from guardianship. However, where a program can demonstrate unique circumstances, indicating that no other entity is available to act as guardian or representative payee, or to provide needed social services, a limited waiver with regard to the provision of social services may be granted by the funder, court or other monitoring agency as to individual wards or beneficiaries. Procedures for granting such waivers shall be designed by the waiver granting agency and shall require a showing that in the absence of a waiver, hardship to the ward will result.

(2) A program providing formal advocacy services shall not serve as guardian or representative payee to any person. The possibility that a ward or beneficiary might need the services of the advocacy program in order to air grievances or to challenge actions of the program in its capacity as guardian is too great to allow such a program to provide guardianship or representative payee services. This prohibition would exclude such programs as legal services providers, ombudsmen, and Protection and Advocacy systems from providing guardianship services.

(3) A program shall not act as the petitioner in a guardianship proceeding, or serve as guardian ad litem or as court appointed

visitor or investigator in a guardianship proceeding. Programs should not be in a position to initiate or influence the appointment of guardians.

(4) A guardian or representative payee shall not commingle personal or program funds with the funds of a ward or beneficiary. This prohibition does not prohibit a guardian or representative payee from consolidating and maintaining a ward's or beneficiary's funds in joint accounts with the funds of other wards or beneficiaries. However, if the guardian or representative payee does so, (s)he shall maintain separate, accurate, and complete accountings of each ward's or beneficiary's funds under his/her control. Where an individual or organization serves several individuals, it may be more efficient and cost-effective to combine the individuals' funds in a single account. In this manner, banking fees and costs are distributed among the individuals, rather than being born by each separately, and higher interest can be earned. The use of such joint accounts should only be permitted where the guardian or representative payee has available personnel with expertise in accounting procedures, so that accurate records are kept of the exact amount of each client's funds in the account and the interest which is attributable to each individual ward or beneficiary. In addition, client accounts shall be audited annually pursuant to Standard 12(J).

(5) A guardian shall not sell, transfer, convey, or encumber any interest in real or personal property to staff of the program, a spouse of a staff member, a board member of the program, a spouse of a board member, an agent or attorney of the program, or any corporation or trust in which the program or its staff has a substantial beneficial interest unless the transaction is approved by the court after notice to interested persons and others as directed by the court.

(6) A program or its staff shall not borrow funds from, or lend funds to, the ward or beneficiary unless the transaction is approved by the court or the agency administering the client's benefits after notice to interested persons and others as directed by the court or the agency. This standard does not prohibit advances made to clients for purposes of off-setting a short-term emergency situation, provided that such advances are made at no-interest.

STANDARD 5. RIGHTS OF WARDS AND BENEFICIARIES

5(A) Rights of the Individual under a Guardianship

In general, a ward retains all legal and civil rights guaranteed to residents under the State and United States Constitutions and all the laws and regulations of the State and the United States except those rights which by court order have been designated as legal disabilities or which have been granted to the guardian by the court. These rights include, but are not limited to:

(1) The right to exercise control over all aspects of his/her life not delegated to a guardian by the court.

(2) The right to be treated with dignity and respect.

(3) The right to guardianship services suited to his/her condition and needs.

(4) The right to privacy -- the right to privacy shall include but is not limited to the right to body privacy, the right to unimpeded, private, and uncensored communication with others by mail and telephone, and the right to visit with persons of his/her choice.

(5) The right to have personal desires, preferences, and opinions given due consideration in decisions being made by the guardian.

(6) The right to petition the court for termination or modification of the guardianship – notification of this right shall include an explanation of the steps necessary to initiate the procedure.

(7) The right to procreate.

(8) The right to bring a grievance against the program (see Standard 12(G)).

Depending on State law, the ward may also have additional rights. The guardian has a duty to request guidance from the court with respect to such additional rights and, where such rights are not clearly removed, to inform the ward of the existence of such rights. These additional rights may include, but are not limited to:

(9) The right to marry.

(10) The right not to undergo sterilization solely for the purpose of birth control.

(11) The right to vote.

(12) The right to execute a will, living will, durable power of attorney, or any other declaration of intent.

(13) The right to retain an attorney.

The guardian shall work to help the ward attain these rights and shall respect these rights at all times. Upon appointment, or at the first meeting between the guardian and the ward, the guardian shall explain the rights to the ward in a manner most likely to be understood by the ward and shall deliver a written copy of these rights to the ward. The guardian shall secure the ward's signature on a copy of the document setting out these rights, which signature shall indicate that the ward has been informed of his rights and delivered a copy of the rights document. In no event shall the ward's signature constitute a waiver of any of the ward's rights. The rights document shall contain a provision stating the same. The guardian shall deliver the signed rights document to the court. If the ward is incapable of signing, the guardian shall obtain the signed statement of a disinterested third party indicating that the guardian provided the ward with a copy of the rights document and shall deliver this statement to the court.

5(B) Rights of the Individual under a Representative Payeeship

(1) An individual subject to a representative payeeship retains all rights guaranteed to State residents under the State and United States Constitutions and all the laws and regulations of the State and the United States, with the exception of the right to receive and manage those funds which are the subject of the appointment.

(2) The representative payee shall explain to the beneficiary at the first meeting of the beneficiary and the representative payee that the beneficiary has the right to petition the agency which appointed the representative payee for termination of that representative payeeship. Notification of this right and an explanation of the steps necessary to initiate the process shall be made both orally and in writing. The representative payee shall secure the beneficiary's signature on a copy of the document setting out these rights, which signature shall indicate that the beneficiary has been informed of his/her rights and delivered a copy of the rights document. In no event shall the beneficiary's signature constitute a waiver of any of the beneficiary's rights. The rights document shall contain a provision stating the same. The representative payee shall deliver the signed document to the

funder of the program and/or to the agency which administers such benefits. If the beneficiary is incapable of signing, the representative payee shall obtain a signed statement from a disinterested third party, indicating that the representative payee has provided the beneficiary with a copy of the rights document and shall deliver this statement to the funder and/or agency administering benefits.

STANDARD 6. INITIAL STEPS

6(A) In the absence of need for immediate action, the guardian or representative payee shall meet with the ward or beneficiary as soon after the appointment as is feasible, but no later than two weeks thereafter. At this first meeting, the guardian or representative payee shall:

(1) Communicate to the ward or beneficiary the role of the guardian or representative payee.

(2) Outline the rights retained by the ward or beneficiary and the grievance procedures available to him/her. A written explanation of the ward's or beneficiary's rights and the grievance procedure shall be given to him/her and, upon request, to relatives, friends, caregivers, and other persons designated by the ward or beneficiary (see Standard 5).

(3) Assess the physical and social situation of the ward or beneficiary, the educational, vocational, medical, and recreational needs, likes and preferences, living conditions, and the support systems available to the ward or beneficiary.

(4) Attempt to gather any missing necessary information regarding the ward or beneficiary. A guardian shall document in writing the following information as required by each individual case and as permitted pursuant to the extent of his/her authority:[5]

(a) client data. This includes such things as names, addresses, and phone numbers of relatives, neighbors, friends and physicians.

(b) functional status. A program having proper authority shall make and record subjective evaluations of the ability of the ward to function in terms of activities of daily living and taking care of personal needs.

(c) medications. A program having proper authority shall compile a list of all prescription and over-the-counter medication administered to the ward or found in the ward's residence. This list shall note the prescribing doctor, the date the medication was issued, the dose size and the frequency with which it is to be taken, the purpose for which it is taken, and any possible side effects. It should also contain observations about the ward's ability to self-administer medications properly.

6(B) Immediately upon appointment or after the first meeting with the ward, the guardian or representative payee shall complete intake by gathering the following information and undertaking the following activities:

[5] The list of information to be gathered is derived in part from the list of inventory forms used by Support Services to Elders, Inc., San Francisco, California. These forms are described and duplicated in: Jack B. McKay and Christine Rouse, Replication Manual (San Francisco: Support Services for Elders, Inc.).

(1) Physician's evaluation. Where the program has proper authority, the ward's treating physician shall be asked to complete a medical evaluation form. This form shall provide the physician with a checklist upon which to note the ward's condition, treatment (including the appropriateness of medication), and functional status. If the ward has not been examined by a physician within the last year, or if circumstances indicate that an examination is needed, the physician shall be asked to examine the ward before completing the form.

(2) Psychological evaluation if appropriate. Where the ward demonstrates psychological dysfunction and the program has the proper authority, a psychological evaluation shall be obtained.

(3) An inventory of property and income. A program having proper authority shall list all the property of the ward, including the amount and type of benefits currently received, the existence and condition of assets, income, pensions, and other financial resources and their location.

(4) An inventory of advance directives. A program having proper authority shall obtain copies of all written statements of intent made by the client. Such statements of intent would include, but are not limited to, powers of attorney, living wills, and organ donation statements.

(5) In general, a representative payee will only need information necessary to insure that benefits are appropriately handled. This will involve gathering information on beneficiary expenses and may involve inquiries into the expenses of dependents and the past debts of the beneficiary.

(6) Client budget. A program serving as representative payee or guardian, and having proper authority, shall design a budget. This budget shall be designed with the help and input of the client.

(7) Notify relevant agencies and individuals of the appointment of a guardian or representative payee. This would include notifying, where appropriate to the scope of the authority granted, providers of residential and in-home services, medical service providers, financial institutions, social service providers, relatives, and others.

(8) The program shall draft an individual client plan outlining the goals of the program and the client, and the target date set for completion of each goal. Plans shall address the unique situation of the ward or beneficiary and shall demonstrate an adherence to the fundamental principles set forth in this document. To the extent possible, the client should participate in formulating the plan. The client plan shall specify:[6]

(a) the specific problems and specific needs of the client;

(b) the appropriate least restrictive conditions and services which are necessary to meet the client's needs;

(c) the means to be employed to meet the service needs of the client -- both in the short-term and the longer term;

(d) the rationale for the provision of less desirable services;

(e) specification of staff responsible for obtaining or providing needed services;

[6] The following provisions of the client plan were suggested by Winsor Schmidt, Director and Associate Professor of Political Science, Center for Health Services Research, Memphis State University, and Erica Wood, Assistant Staff Director, American Bar Association Commission on Legal Problems of the Elderly. Provisions were also adapted from the Model Guardianship and Conservatorship Statute, prepared by the Developmental Disabilities State Legislative Project of the ABA Commission on the Mentally Disabled §§17(2)(a) - (b) (1979).

(f) the manner in which the guardian or representative payee will exercise and share decisionmaking authority with the ward or representative payee, where possible;

(g) the minimum conditions for limiting or terminating the guardianship and/or representative payee service and the probability of such an occurrence;

(h) such other items as will assist in fulfilling the needs of the client and the duties of the guardian or representative payee.

The client plan shall be reviewed at the next scheduled review of cases (see Standard 14(A)). The individual client plan shall be submitted to the court or the agency responsible for administering the benefits which are the subject of a representative payeeship and to any other relevant parties as determined by the court or the benefit-administering agency.

STANDARD 7. PERSONAL CONTACT AND ONGOING RESPONSIBILITIES

7(A) The guardian or representative payee shall formulate short and long range plans for the ward or beneficiary in accordance with Standard 6(B)(8) and shall engage in ongoing activities and responsibilities to effectuate those plans. Through personal contact with the ward or beneficiary, the guardian or representative payee shall continually monitor the ward's or beneficiary's situation, assessing the continued benefit of current plans. The guardian or representative payee shall promptly make changes in the ward's or beneficiary's situation, or secure services, in order to ensure that mechanisms, situations and/or courses of action which comport with the principle of substituted judgment are instituted or, in the absence of reliable evidence of the ward's or beneficiary's views prior to appointment of the guardian or representative payee, that mechanisms, situations and/or courses of action which are in the best interests of the ward or beneficiary are secured.

7(B) A program shall work cooperatively with other surrogate decisionmakers, including another guardian and/or representative payee, to further the interests of the individual.

7(C) Guardians of the person shall have meaningful visits with their wards no less than once a month. Guardians of the estate shall have meaningful visits with their wards no less than quarterly. Representative payees shall visit with beneficiaries no less than quarterly. Visits by guardians of the estate and representative payees will be made for the purpose of ensuring that all goods and services for which payment is made are properly delivered and rendered.

7(D) Where the guardian or representative payee has proper authority, a meaningful visit shall consist of, but is not limited to, the following activities:

(1) Communication with the ward or beneficiary. In communications with the ward or beneficiary, the guardian or representative payee shall, where appropriate to the authority granted, make every effort to ascertain the ward's satisfaction with the current living situation, the extent of the ward's or beneficiary's current disability or impairment, and the current needs and desires of the ward or beneficiary.

(2) Conferences with service providers/caregivers. Where applicable, this may include conversations with physicians, psychologists, nurses, social workers, physical or occupational therapists, teachers, and residence operators. If care conferences are held at the living site, the guardian shall ask to be informed of their scheduling and make every attempt to attend and participate in care conferences concerning wards. If unable to attend, the guardian shall obtain information about what occurred at the conference.

(3) Examination of any charts or notes kept regarding the ward.

(4) Assessment of the appropriateness of maintaining the ward in the current living situation considering social, psychological, educational and vocational, and health and personal care needs. In making this assessment the guardian shall consider all other factors listed in Standard 8.

(5) Assessment of ward's physical appearance and psychological and emotional state.

(6) Assessment of the repair, cleanliness, and safety of the living situation.

(7) Assessment of the adequacy and condition of the ward's personal possessions. This would include such items as clothing, furniture, TV, etc.

7(E) The guardian or representative payee shall keep a written summary of all personal contact with the ward or beneficiary, whether in person or by phone, and with other care providers. This summary shall be kept in an orderly manner accessible for use by the program and for review by the court and shall describe the date and approximate time of the contact, the reason for the contact, the nature of the contact, and the outcome or result of the contact.

7(F) Guardians and representative payees shall petition the court or the agency for limitation or termination of the guardianship or payeeship when the ward or beneficiary no longer meets the standard pursuant to which the guardianship or payeeship was imposed, or when there is an effective less restrictive alternative available.

STANDARD 8. WARD'S LIVING SITUATION

8(A) Guardian of the Person's Duty to Monitor the Living Situation

Where the guardian has appropriate authority, he/she shall carefully monitor the living situation of the ward. The following factors should be examined and evaluated in monitoring the ward's living situation:

(1) The ward's wishes with respect to his/her living situation.

(2) Where the ward is in a facility, the quality of life offered by that facility. In making this determination, consideration should include, but is not limited to:[7]

(a) the opportunity for active habilitation and rehabilitation to maximize the ward's potential to return to independent living. This includes, but is not limited to, the availability of support services, physical therapy, occupational therapy and counseling, and recreational, educational and productive activities, especially individually designed activities, appropriate to the ward's needs and interests, designed to promote opportunities for engaging in normal pursuits including religious activities of the ward's choice;

(b) the atmosphere and physical condition of the living situation including, but not limited to, such aspects as cleanliness, freedom from pests, safety, comfort, homelike atmosphere, availability of windows and light, availability of secure and private closet space, accessibility to the outdoors, the setting

[7] The list enumerated here is derived in part from the "Proposed Conditions of Participation of the Health Care Financing Administration" published in the Federal Register, October 16, 1987.

and surroundings in which the residence is located, and upkeep of the buildings and furnishings;

(c) treatment of the ward by staff and other residents. This should include consideration of whether the ward is treated with dignity and respect and in an age-appropriate manner;

(d) the appropriateness of the peer group;

(e) opportunity for privacy and exercise of self-determination by the ward. Among other things, this should include consideration of such factors as whether the ward is allowed: to select friends and visit with family and friends both inside and outside the facility; to control personal money; to have personal possessions; to choose activities, schedules and health care consistent with his/her interests, assessments and plans of care; and to have reasonable body privacy;

(f) opportunity for independence offered by the living situation;

(g) availability of culturally appropriate food prepared by methods that conserve nutritive value, flavor, and appearance and that is served in a manner that is attractive and at the proper temperature;

(h) opportunity afforded the ward to influence decisions made about the facility, e.g. to participate on a residents' council;

(i) compliance by the facility with state and federal laws pertaining to residents' rights.

(3) Whether the living situation provides the most appropriate, least restrictive living arrangement available.

(4) Whether the living situation meets the needs of the ward with minimal needed intrusion on the privacy and autonomy of the ward. In making this determination the availability of needed support systems shall be considered. Support systems include, but are not limited to, the help and care given by family and friends, social and in-home services, medical and psychological services, and transportation services.

(5) The physical condition of the living situation, including cleanliness, repair, and safety.

(6) The effect a change in living situation would have on the ward's psychological, emotional, social, and physical condition.

(7) The geographical proximity of the living situation to visiting family and friends.

(8) The effect the geographical location of the living situation has on the guardian's ability to see to the care, comfort, and maintenance of the ward.

8(B) Authorizing a Move to a More Restrictive Environment

A guardian having the appropriate authority shall not authorize moving the ward to a more restrictive environment until (s)he has carefully considered the factors listed in Standard 8(A) and has consulted with professionals actively involved with the care of the ward. A more restrictive environment is an environment which places greater limits on the ward's rights and personal freedoms. Prior to authorizing the move, the guardian should make every effort to consult with an objective third party, who has considered the factors listed in Standard 8(A), on the advisability of such move. As noted in the definition section, the objective third party may be any person or group which has no interest, financial or otherwise, in the resulting actions or services undertaken pursuant to a particular guardianship decision and which is not involved in the day-to-day delivery of

services to wards or the operation of the program as a whole. Accordingly, the objective third party cannot be affiliated with the current or prospective residence of the ward. The objective third party might include: the probate judge; a court visitor, investigator, or other monitor of guardianship services; a committee of community advisors; or a consulting social worker or other health professional.

8(C) Need for Court Approval Before Placement in a More Restrictive "Facility"

If a guardian having the appropriate authority determines, based on the factors listed in paragraph 8(A), that the ward should be placed in a more restrictive "facility", the guardian shall first seek the approval of the court before placing the ward in the "facility." A more restrictive "facility" is a "facility" which places greater limits on the ward's rights and personal freedoms. In seeking such approval, the guardian shall make known to the court the recommendation of the objective third party, consulted pursuant to Standard 8(B). In no event shall a guardian admit a ward to a facility for the inpatient treatment of persons who are mentally ill without an involuntary commitment proceeding as provided by State law.

8(D) Emergency Or Forced Move

A guardian having the authority to determine the living situation of a ward shall be aware of State and federal laws and regulations pertaining to the involuntary transfer or discharge of residents of facilities and shall pursue administrative and judicial remedies available under such laws if (s)he feels that the individual is being forced to move without proper cause.

STANDARD 9. SECURING MEDICAL SERVICES AND AUTHORIZING MEDICAL TREATMENT[8]

9(A) Duty to Promote the Maintenance of the Ward's Health

A guardian having appropriate authority has the duty to actively promote the maintenance of the ward's health. This includes not only the duty to react to any medical situations which demand attention, securing and authorizing necessary medical treatment, but in addition the duty to ensure the ward receives regular preventive medical and dental services. Accordingly, a guardian shall ensure that the ward undergoes annual dental and medical exams. If the ward is a resident of a facility or a patient in a hospital, the guardian shall periodically examine the medical records of the ward and speak with attending physician(s) and other caregivers to ensure that the ward is receiving proper and necessary medical care.

9(B) Criteria for Making Medical Decisions

A guardian having appropriate authority shall proceed in the manner indicated when called upon to make a medical decision for a ward:

(1) The guardian's decision shall be controlled by any specific wishes of the ward, expressed prior to appointment of a guardian, including but not limited to wishes expressed in a living will, a durable power of attorney, or any other specific oral or written declaration of intent.

(2) If the ward made no specific declaration of intent prior to appointment of a guardian, the guardian shall use whatever general knowledge (s)he has of the ward to make a decision based on a substituted judgment standard. Such standard shall allow

[8] Standard 9 was derived with the help of agency policy of the Kalamazoo County Guardian, Inc., Kalamazoo, Michigan and the Illinois Office of State Guardian Official Policies and Procedures.

consideration of the current wishes of the ward. In soliciting the ward's wishes the guardian shall first inform and explain to the ward the details of the information gathered in Standard 9(B)(3) below. In addition, the guardian should encourage the ward to put such wishes in writing for future reference by guardians, courts, health care professionals, and others.

(3) Where reliable evidence of either the ward's prior specific or general wishes does not exist, the guardian shall make a decision based on the perceived best interests of the ward. In determining the best interests of the ward the guardian shall consider the current wishes of the ward. The guardian shall make an informed judgment and shall not consent to treatment until the following information has been gathered:

(a) the reason for, and nature of, the treatment;

(b) the benefit/necessity of the treatment;

(c) the possible risks and side effects of the treatment;

(d) alternative treatments or measures that are available and their respective risks, side effects and benefits.

In determining any of the above factors, the guardian should consider information arising out of personal contact with the ward, information arising out of the contact of family or close friends with the ward, information and opinions imparted by attending physician(s) and/or relevant medical professionals, and all other relevant information.

9(C) Decisions About Medical Interventions that Can Be Made Without a Second Opinion

Certain medical interventions if performed without anesthesia or with only a local anesthetic may be authorized by the guardian alone, considering the factors listed in paragraph 9(B), and do not require the guardian to obtain a second medical opinion. If the ward has made a prior specific declaration of intent with regard to the issue at hand, that declaration shall be controlling. Unless State law requires the guardian to undertake additional steps before authorizing a specific medical intervention, this paragraph applies to the following medical interventions:

(1) Diagnostic physical examinations.

(2) Eye examinations.

(3) Limited use of x-rays.

(4) Routine dental examinations. This would include such things as teeth cleaning, bridgework, fillings, crowns, replacement of dentures, etc.

(5) Physical therapy.

(6) Minor medications, both prescription and non-prescription. This would include such medications as aspirin, cold medications, vitamins, penicillin, etc.

(7) Routine, low risk immunizations.

9(D) Decisions About Medical Interventions Requiring a Second Substantiating Opinion

Absent an emergency or execution of a living will, durable power of attorney or other declaration of intent which clearly indicates the ward's desires with respect to that action, a guardian having the appropriate authority shall not grant or deny authorization for the following medical interventions until (s)he has given careful consideration to the factors listed in paragraph 9(B) and has obtained two substantiating medical opinions from physicians who have examined the ward, at least one of whom is not affiliated with a health care institution in which the ward is placed. Unless State law requires the guardian to undertake additional steps before authorizing a specific medical intervention, this paragraph applies to the following medical interventions:

(1) Medical interventions requiring general or major anesthesia or involving a moderate to significant risk to the ward.

(2) Administration of potentially damaging drugs, regimen, or therapy.

(3) Extensive use of x-rays.

(4) Interventions which drastically affect the appearance or functioning of the ward, such as surgery, amputation, eye surgery, and cosmetic surgery.

(5) Any treatments which require restraints, whether chemical or mechanical, or any adversive behavior modification. Before these treatments shall be authorized the guardian shall explore and exhaust all less restrictive alternative interventions.

(6) Interventions which pose a significant risk to the ward due to the ward's condition or unique vulnerabilities. By way of illustration, unique conditions or vulnerabilities would include such things as allergic reactions, poor health, bleeding problems, and heart conditions.

(7) Administration of anti-psychotic or psychotropic drugs.

(8) After-death donations of organs.

(9) Prescription of contraceptives if deemed medically necessary.

(10) Any other treatment or intervention which would cause a reasonable person to seek a second medical opinion.

9(E) Emergency Medical Treatment

In the case of emergency medical treatment falling within any of the situations listed in paragraph 9(C) or 9(D), a guardian having proper authority shall grant or deny authorization of medical treatment based on a reasonable assessment of the factors required by paragraph 9(B), within the time frame allotted by the emergency. In all emergency situations the guardian shall speak with the treating or attending physician before authorizing or denying any medical treatment. If State law provides for the performance of additional steps prior to granting or denying authorization, the guardian shall undertake such additional steps.

9(F) Extraordinary Medical Actions Requiring Prior Authorization By the Court

Extraordinary procedures cannot be undertaken without prior authorization from the court, unless the ward has executed a living will or durable power of attorney which clearly indicates the ward's desire with respect to that action. This would be most likely to cover those situations in which "do not resuscitate" orders might be applicable or in which removal of life support is contemplated. Unless State law requires the guardian to undertake additional steps before authorizing a specific medical intervention, this paragraph applies to, but is not restricted to, the following medical interventions:

(1) Organ transplants to or from a living ward.

(2) Entry of do not resuscitate orders.

(3) Experimental treatment.

(4) Removal of life support.

(5) Abortion.

(6) Hysterectomy or any other treatment which would have the side effect of rendering the person incapable of procreation, provided it is medically necessary and is not for the purpose of birth control.

(7) Medical treatment for persons whose religious beliefs prohibit such treatment. By way of illustration this would include blood transfusions for a Jehovah's Witness or medical treatment for a Christian Scientist.

(8) Any other treatments or interventions which the court must approve pursuant to State law.

In the absence of a clear legal directive from the ward (i.e. living will or durable power of attorney) in the above listed instances, the guardian shall elicit the written opinion of the hospital or nursing home ethics committee, if one exists, before bringing the matter before the court.

STANDARD 10. DISPOSITION OF PROPERTY

10(A) If reliable evidence exists of the ward's views prior to the appointment of a guardian, the guardian of the estate, having the appropriate authority, shall not sell, encumber, convey, or transfer property of a ward, or an interest therein, unless such sale, encumbrance, conveyance, or transfer is in keeping with the principle of substituted judgment.

10(B) In the absence of reliable evidence of the ward's views prior to the appointment of the guardian, the guardian of the estate, having the appropriate authority, shall not sell, encumber, convey, or transfer property of a ward, or an interest therein, unless such sale, encumbrance, conveyance, or transfer is in the best interest of the ward. In considering whether it is in the best interests of the ward to dispose of property, either real or personal, the guardian shall consider, but is not limited to a consideration of, the following factors:

(1) Ability of the disposition of the property to improve the life of the ward.

Item 3

Congressional Research Service
The Library of Congress

Washington, D.C. 20540

February 24, 1989

TO : House Select Committee on Aging, Subcommittee on Housing and Consumer Interests
Attention: David Dean

FROM : Carol O'Shaughnessy, Richard Price, and Carmen Solomon
Specialists in Social Legislation
Education and Public Welfare Division

SUBJECT : **Chronology of Significant Federal Activities Related to Board and Care Homes**

This is in response to your request for a chronology of significant Federal activities related to issues on board and care facilities.

The chronology begins with the enactment of the Keys amendment in 1976. It contains information on relevant Federal activities related to implementation of the Keys amendment, as well as enactment of provisions under other laws related to the Keys amendment, such as under the Older Americans Act and Medicaid.

Also listed are major federally sponsored research efforts in the area of board and care and an administrative action taken by former Secretary Schweiker to improve the quality of care in such facilities (Eight Point Program to Improve Implementation of HHS's Keys Amendments Responsibilities). We did not include references to the results of the research cited nor to the impact of the Eight Point Program. Note that some of the actions identified in the Eight Point Program were never implemented, such as the withholding of Older Americans Act funds in the event of State noncompliance with the Keys amendment and the directive that State standards for board and care facilities be sent to the Administration on Aging (AoA).

Note that there are other research and demonstration efforts on board and care issues which are not reflected here. For example, AoA awarded funds in 1987 to the Florida Department of Health and Rehabilitative Services to study quality of care in domiciliary homes. There may be other such research efforts which we have not identified.

We hope this information is of assistance to you.

CHRONOLOGY OF SIGNIFICANT FEDERAL ACTIVITIES RELATED TO BOARD AND CARE HOMES, 1976-1988

1976 (October 20) Section 1616(e) of the Social Security Act, known as the Keys Amendment, was enacted as part of P.L. 94-566, the Unemployment Compensation Amendments of 1976. The Keys Amendment requires each State to establish or designate one or more State or local authorities to establish, maintain or insure the enforcement of standards (governing such matters as admission policies, safety, sanitation, and protection of civil rights) for group living arrangements in which a "significant number of Supplemental Security Income (SSI) recipients is residing or is likely to reside."[1] It requires States to make available for public review a summary of the standards. It also requires each State to certify annually to the Secretary of the then Department of Health, Education, and Welfare (HEW) that it is in compliance with the requirements of the Keys Amendment. In addition, the Keys

[1] In the same law (P.L. 94-566) Congress modified the original ban on SSI benefits for persons living in public institutions by excluding from the definition of public institution "a publicly operated community residence which serves no more than 16 residents."

Amendment requires that a recipient's SSI benefit be reduced by an amount equal to State payments for medical or remedial care provided by the board and care facility if the SSI recipient resides in a facility that is not approved as meeting the health and safety standards mentioned above. (The Keys Amendment became effective October 1, 1977.)

1977 (June 8) A hearing was held before the House Select Committee on Aging, The National Crisis in Adult Care Homes, 95th Congress, 1st Session.

1978 (January 31) The Department of HEW issued final regulations on standard-setting requirements for medical and non-medical facilities where SSI recipients reside (i.e., the Keys Amendment). According to the Federal Register summary of the regulations, the purposes of the regulations are: (a) to encourage development of safe and appropriate residential settings as an alternative to institutional living for appropriate elderly and handicapped children and adults; (b) to limit the use of SSI funds for substandard facilities for such persons; and (c) to publicize the standards and their enforcement procedures through the public review process of the Title XX annual services plan.

1978 (February 10) A hearing was held before the House Select Committee on Aging, Adult Boarding Homes, 95th Congress, 2d Session.

1978 (October 1, date grant period began) **The Administration on Aging** (AoA) awarded a grant to the Hebrew Rehabilitation Center for the Aged to conduct a nationwide study of domiciliary care. One of the objectives of the study was to assess the appropriateness, adequacy, and quality of domiciliary care services.

1978 (October 18) The Older Americans Act was amended (by P.L. 95-478) to require State agencies on aging to establish and operate a long-term care ombudsman program to investigate and resolve complaints of residents in long-term care facilities. Long-term care facilities were defined as skilled nursing facilities and intermediate care facilities, and "any other similar adult care home."

1979 (April 25) A hearing was held before the House Select Committee on Aging, Fires in Boarding Homes: The Tip of the Iceberg, 96th Congress, 1st Session.

1979 (September) The Office of the Assistant Secretary for Planning and Evaluation in the then Department of HEW awarded a contract to the Denver Research Institute to review board and care homes. One of the objectives of the project was to collect, review, and assess State standards used to evaluate board and care facilities pursuant to the Keys Amendment.

1979 (September 30, date contract period began) The Social Security Administration (SSA) contracted with the Hebrew Rehabilitation Center for the Aged to ascertain how States with SSI supplementary programs supervise board and care facilities.

1979 (November 19) The General Accounting Office (GAO) issued a report entitled Identifying Boarding Homes Housing the Needy Aged, Blind, and Disabled: A Major Step Toward Resolving A National Problem. The purpose of the GAO review was to ascertain how the location of boarding homes which house significant numbers of SSI recipients could be identified in order to develop an approach to implement the Keys amendment. GAO also tested the usefulness of a computerized data retrieval system to apply to SSA records in order to identify addresses where SSI checks were being sent each month.

The GAO report made the following recommendations: The Secretary of HEW should (1) notify each State that a data retrieval process using SSA State Data Exchange files can be used to identify boarding homes housing SSI recipients; (2) provide computer and programming assistance to any State lacking the capability to manipulate the State Data Exchange file to produce data in a format usable for identifying potential boarding homes; and (3) monitor States' efforts to enforce the Keys amendment and help resolve problems encountered.

1981 (January) The Health Care Financing Administration (HCFA) signed an interagency agreement with the National Bureau of Standards (NBS) to develop a Fire Safety Evaluation System for board and care homes.

1981 (March 9) A hearing was held before the House Select Committee on Aging, Boarding Home Fires: New Jersey, 97th Congress, 1st Session.

1981 (March-September) HCFA entered into an agreement with the Federal Emergency Management Agency (Fire Administration) to convene a task force to identify and prioritize key issues relative to fire safety in board and care homes.

1981 (June 25) A hearing was held before the House Select Committee on Aging, Fraud and Abuse in Boarding Homes, 97th Congress, 1st Session.

1981 (July 28) A hearing was held before the House Select Committee on Aging, Oversight Hearing on Enforcement of the Keys Amendment, 97th Congress, 1st Session.

1981 (August 13) Title XX of the Social Security Act was amended (by P.L. 97-35) to become a block grant program for social services to States. Many requirements that existed prior to enactment of the block grant provisions were eliminated, including a requirement that States submit Title XX plans to the Federal government. This change removed the vehicle to which States were to attach a summary of their standards for board and care homes pursuant to the Keys Amendment.

1981 (August 13) The Medicaid program was amended (by P.L. 97-35) to authorize States to cover a broad range of home and community-based services for persons who would otherwise be eligible for nursing home care or other institutional care under the State's Medicaid plan. These services are often referred to as "2176 waiver services," and can be provided in a variety of community settings, including board and care homes. In order to provide these services, States must make special application to the Secretary of Health and Human Services (HHS) and provide the Secretary a number of assurances. Among other things, Medicaid law requires States to assure that they will take necessary safeguards to protect the health and welfare of individuals served.

1981 (December 29) The Older Americans Act was amended (by P.L. 97-115) to require that State long term care ombudsman responsibilities under the title III program include investigation and resolution of complaints of residents in board and care facilities. The law defined these facilities as including "any category of institutions regulated by a State pursuant to the provisions of section 1616(e) of the Social Security Act," the Keys Amendment.

1982 (April) The Office of the Inspector General in the Department of Health and Human Services (HHS) issued a report entitled, Board and Care Homes, A Study of Federal and State Actions to Safeguard the Health and Safety of Board and Care Home Residents.

The report made the following recommendations: (1) HHS should designate a single unit within the Department to be responsible for board and care activities; (2) HHS should identify a specific mechanism for States to use to publish standards for board and care homes as specified by the Keys amendment (since title XX no longer required States to submit State plans to the Federal government); (3) HHS should consider an alternate method of sanctions to facilitate enforcement of the Keys Amendment, other than penalties levied against SSI recipients as called for by the Keys Amendment; (4) the Secretary should grant home and community-based waivers under the Medicaid program for services in board and care facilities only in cases where such facilities meet standards as defined by the State; (5) SSA should approve representative payee status to board and care proprietors only if the proprietors submit to SSA evidence of compliance with applicable State standards; (6) HHS should provide assistance to States in their efforts to assure quality care in board and care facilities; (7) HHS should develop a model statute governing standards in board and care facilities; (8) HHS should continue funding to the NBS for development of model fire safety standards for board and care homes.

1982 (April 21) The Secretary of HHS, Richard Schweiker, issued an 8-point program to improve implementation of the Keys Amendment and to respond to the recommendations of the Inspector General's report (Memorandum from the Secretary, Eight-Point Program to Improve Implementation of HHS's Keys Amendment Responsibilities).

The program included the following: (1) AoA would become the Federal entity to receive the States' summary of board and care standards under the Keys amendment; (2) Older Americans Act funds would be subject to sanction in the event of noncompliance with the Keys amendment; (3) board and care home proprietors would be approved as protective payees for SSI funds only if the proprietors submit to SSA evidence of compliance with State standards; (4) HCFA would be prohibited from approving home and community-based waivers for board and care under Medicaid, unless the State certified that board and care facilities are in compliance with State standards; (5) HHS would contract for the development of a model State statute for board and care facilities; (6) HHS would conclude fire safety research efforts with the NBS; (7) the Office of Human Development Services (OHDS) would be responsible for providing technical assistance to States on board and care activities; and (8) a unit within OHDS would be responsible for coordinating Departmental efforts for board and care activities.

1983 (March 1) In response to the deletion of the reference to Title XX in the Keys Amendment (by P.L. 95-35), the OHDS issued a final rule, with a 60-day comment period, on standard setting requirements for medical (not certified for Medicare or Medicaid) and nonmedical facilities where SSI recipients reside (i.e., the Keys Amendment) to specify how States must now comply with the Keys Amendment. The rule said that in addition to making the summaries of the standards available for public review, a State must send the summaries of the standards and of the enforcement procedures to the Assistant Secretary of OHDS. It also required States to designate a State official to assist in the implementation of the requirements of the Keys Amendment.

1983 (March) The NBS issued its report on fire safety in board and care homes, entitled A Fire Safety Evaluation System for Board and Care Homes (Report NBS-IR-83-2659). (This project was funded over a number of years by various Federal agencies including the Administration on Developmental Disabilities (ADD) and HCFA. The NBS system was subsequently adopted by the National Fire Protection Association as part of its life safety code.)

1983 (March-April) The American Bar Association (ABA) under a grant from HHS conducted a survey of the States to determine how States regulated board and care facilities. The findings were published in "Board and Care Report: An Analysis of State Laws and Programs Serving Elderly Persons and Disabled Adults." The survey was the first step in the ABA's development of a model statute on the regulation of board and care facilities.

1983 (November 30) In response to comments made on the rule on standard setting requirements for medical and nonmedical facilities where SSI recipients reside, the OHDS published a final rule allowing States to charge a fee for providing copies of standards, procedures, or other information on board and care facilities.

1984 (March-April) A document prepared by the ABA for the Department of HHS, entitled, A Model Act Regulating Board and Care Homes: Guidelines for States, was published.

1985 (March 13) The Secretary of HHS issued final regulations pertaining to the Medicaid home and community-based waiver program. These regulations require States to assure that all board and care facilities covered by the Keys amendment, in which Medicaid home and community-based services are provided, are in compliance with applicable State standards for board and care facilities.

1987 (November 29) The Older Americans Act was amended (by P.L. 100-175) to require the Commissioner on Aging to conduct a study of the impact of the long-term care ombudsman program on residents of board and care facilities and other similar adult care homes. The study is to include recommendations for expanding and improving ombudsman services in such facilities. The law requires the study to be submitted to Congress by December 31, 1989.

1988 (March) As part of the work of the Interagency Committee on Developmental Disabilities chaired by ADD, a subcommittee on fire safety in board and care homes was convened. The subcommittee has recommended that the Federal government undertake an evaluation of the extent to which States have adopted and are using the evaluation system for fire safety in board and care homes issued by the NBS in March 1983 (see above). To date, a number of Federal agencies, including ADD, AoA and HCFA have committed funds for this project. Other agencies are currently in the process of assessing their ability to commit funds for the project which would be undertaken by the NBS.

Item 4

Testimony on Board and Care
Senate - House Joint Hearing, Committees on Aging
March 9, 1989
Presented by Barbara B. Jameson, Ph.D.
National Association of Residential Care Facilities

The National Association of Residential Care Facilities welcomes Congressional attention to the issues surrounding housing and supportive services for the elderly and mentally and physically disabled adults. State Provider associations and individual caregivers in states across the country have advocated for these vulnerable populations and feel that more of the nation's resources need to be allocated for quality care.

Licensed residential care facilities have developed as a significant component of the nation's housing & long-term care services. They have been an important non-medical alternative to nursing homes for elderly who are not in need of skilled nursing care, and for the chronic mentally ill who would otherwise be in institutions or on the street. Ideally, residential care facilities are family-like, quality environments, that utilize other appropriate community resources, and encourage independent functioning to the fullest extent possible.

Providers of these care services, through their state and national associations, are endeavoring to provide services of increasing quality. Some 600 providers around the country are enrolled in our Administrator Certification Program, which requires 40 contact hours of instruction on some 12 content areas. At the same time, given economic pressures, providers are also concerned about the trend to a dual system, one track for low-income persons, a separate track for those who can afford to pay private fees, with a consequent differential in quality of care.

We believe there are a number of issues that need to be addressed. We would hope that in future hearings, the Senate and House committees on Aging will look at how federal involvement can clarify and enhance the environments for these citizens.

We have heard a great deal in these Hearings about resident abuse, poor quality facilities, and lack of state agency monitoring. In looking at how to overcome these problems, we must first look at the context of these accusations. There are three general categories:

1. Licensed residential care facilities. (Board and care)
2. Unlicensed homes (giving personal care but with no official sanction).
3. Rooming houses, SRO's, senior housing, etc. (housing which offers no additional support).

It is important to understand these differences because the solutions to problems differ according to category.

In the case of licensed care facilities, if they do not meet standards of human decency, solutions should be viewed in terms of A) need for better regulations, B) need for monitoring and enforcement of regulations, C) increased public funding for low income residents, and D) better training for the staff of licensed care homes.

In states with a large number of unlicensed facilities that claim to or do give personal care, the solutions can be found in A) incentives for being licensed, B) efforts to find and require facilities that should be licensed, C) instructions to social workers not to make placements in non-licensed care homes, and D) tighter definitions of who needs to be licensed, including facilities for private pay residents.

The issue of very poor housing, where poverty stricken elderly and mentally disabled live, are part of the scandal of lack of housing for low income people. There is also a lack of understanding on the part of many placement workers of the role of licensed care homes. For example, the unfortunate people in Sacramento who were placed in Mrs. Puentes rooming house probably should have been in a licensed care home. Placement staff should not assume that a person's independence is taken away if they are placed in residential care. Residential staff need to be trained to encourage independence, but good supportive services can prevent further deteriorization. Also, because a person is alcoholic, very frail, or chronically mentally ill, does not mean that they are not worth the extra funds needed for protection in a licensed home. There was a licensed care home around the corner from Mrs. Puentes'. Did those poor men not deserve such a placement? Didn't the two women in D.C. who struggled in a pest infested rooming house at least deserve a licensed care home. The licensing component, at minimum, provides a basis for government action if proper standards are not met.

A sample of other issues that should be addressed are as follows:

1. Since many homes caring for the low income, SSI recipient are managing to give quality care, what are the ingredients of a successful home versus a poor quality licensed home? (Example, size, type of staff, kind of resident, available community support services).

2. Are there incentives that can be built into the system to reward private pay facilities that want to include some SSI residents in their homes? Currently such homes are being "punished" because private pay residents can no longer be charged enough to cover the loss for SSI residents and the extra paper work for taking SSI residents is a disincentive in and of itself.

3. Can new creative ways be found to meet the need for guardianship or designated payee? Most facility operators do not seek the responsibility, but fill a vacuum.

4. Can national guidelines be developed that would give consistency to licensed care homes in overseeing medications, to the training of staff, to fire safety requirements, and to a level of support for activities of daily living.

5. Can federal guidelines and incentives be developed to increase the number of facilities that maintain the characteristics of a family; that is, caring relationships, concern for all aspects of a person's life, and encouragement of self-sufficiency and responsibility for self. Can ways be found to maintain accountability without converting residential care facilities into "institutional environments?"

Because so many elderly and chronic mentally ill persons will be isolated and vulnerable to a range of abuse and neglect without quality residential care facilities, finding solutions to these issues is important to us all.

The hard working and concerned caregivers that provide quality residential care want to work with Congress to assure that every person who needs a safe environment, special personal care, and community services have that opportunity, regardless of their financial resources, geographic location, or special problem.

NARCF asked associations to supply information on the current status of support for low income residents in their state, the inspection process, and legislative initiatives. Ten states were able to reply in time for this hearing.

Significant variation in the number of licensed care home residents receiving SSI and other benefit rates is found between states. The spectrum ranged from a high of 73% of residents in Colorado to a low of 3.5% in Rhode Island, where SSI payments are not high enough for the services of licensed care homes. On the average, 54% of the residents in these facilities are currently receiving SSI and other benefits.

Reimbursement to providers also varies notably from a high of $55.00/per day in Connecticut to $388.00/month in select counties of Tennessee (less than $13.00/day). A table compiled by NARCF of SSI payments with optional state supplements added has been attached to this testimony for review. Personal allowances also range from a high of $124.00/month in Connecticut to a low of $24.00/month in South Carolina. Residents are also expected to purchase clothes, and other personal items such as cigarettes from this allowance. licenThe cost of licensed residential care compared to other types of care in the long term care system differ greatly for appropriate populations, RCF's are far more economical. The differentials in funding in North Carolina are illustrated in the table below:

1) Skilled Nursing Facilities (SNF)	$ 1,871.70/Mo. 2)
Intermediate Care Facilities (ICF)	$ 1,355.10/Mo. 3) Rest
Homes (Home for the aged and Family Care)	$ 678.00/Mo.
4) Intermediate Care Facilities for the Mentally Retarded (ICF/MR)	$ 4,258.33/Mo.
5) Home Health Care (HHA)	$ 54.00/Vst. RN,LPN,PT OT,ST;and
	$ 30.00?Vst. for aide
6) LICENSED RESIDENTIAL CARE FACILITY	$ 687.00/Mo.

Adequate funding is of utmost importance to resident and provider. Costs are on the upswing, yet pending legislation as in Connecticut, for example, is attempting to reduce state spending by 5% in the following ways:

A) Lower the fair rental value rate of return component on a prospective and retrospective basis;

B) Eliminate the return on equity component;

C) Eliminate the efficiency adjustment component;

D) Lower the real wage growth percentage component;

D) Lower the GNP deflator percentage component.

Similarly, in Nevada a bill designed to raise the monthly reimbursement to residential care facility providers by $50.00/month has been pending since 1979.

Also, for those residents that move into licensed care facilities, assistance programs such as food stamps, home heating oil and chore services are discontinued. Furthermore, while non profit organizations enjoy discounts and sales tax exemptions, for-profit licensed RCF's that often have fewer resources do not. In other words, the federal government actually saves money by witholding benefits in licensed care that other elderly recieve and by taxing those operations.

Nationwide, facilities that seek licensing are often compelled to modify their premises in order to comply with local construction and fire regulations. While compliance is essential, federal low interest loans must be made available in order to aid facility operators in meeting these standards. Furthermore it is important to note that frequently the same standards and regulations are applied to all care facilities, regardless of size, within a given state. Facility capacities can range from less than five beds to large units of over two hundred residents. Consequently the application of blanket operating criteria to all licensed facilities statewide is unrealistic.

In order to maintain quality, licensed residential care facilites should be monitored so that regulations are consistently adhered to. There was great variation in the number of inspectors per favcility. Tennessee led reporting states with 67 RCF's, or (708 beds) per inspector. Whereas Connecticut has the lowest ratio of 5 RCF's, or (128 beds) per inspector. New Hampshire has the lowest ratio with, 126 beds or 20 Rcf's per inspector. Legislation is needed to asure more efficient oversight.

A positive note is Virginia legisletion HB 1420 that allows semi mobile residents to reside in licensed residential care facilitiesif these meet safety and fire codes. While a step in the right direction such laws are overshadowed by the plight of the chronically mentally ill. Current federal legislation will force the release of numerous mentally ill residents from nursing homes. As a result most of these people will settle in residential care facilities. If quality care is to be provided to them prompt action on the part of the legislature is necessary in order to assure funding, training and useful regulations to the licensed residential care facility industry.

Item 5

Arkansas Department of Human Services
Division of Economic and Medical Services

Seventh and Main Streets
P.O. Box 1437
Little Rock, Arkansas 72203-1437

Bill Clinton
Governor

Walt Patterson
Director

Kenny Whitlock
Deputy Director

March 7, 1989

Mr. John Monahan
Senate Special Committee on Aging
Dirksen Senate Office Building
Room G31
Washington D.C. 20510

Dear John:

I would like to thank you for your interest in the residential care program and for allowing me to have an input.

I have only been in the residential care program for 2 1/2 years, but prior to that I was in the nursing home program for 16 years with the last 8 of those years as Administrator of that program. In these 2 1/2 years I have found that the regulations developed by the Office of Long Term Care have produced some outstanding facilities and provided a mechanism to close several substandard facilities. The licensed Residential Care Facilities in Arkansas are "homes" that the elderly can feel safe and secure in. I feel that the residential care program is the greatest program ever developed for the elderly and most of the residents in our residential care facilities would agree.

The residential care program has often been referred to as an alternative to nursing home care, I strongly disagree, it is a totally new concept. It is a program for people who do not need nursing home care. The people residing in residential care must be independently mobile, able to self-administer their own medication, unable to live independently for a variety of reasons and require some supervision. If many of the elderly would avail themselves of this service, in all probability they would never require nursing home placement. Many of the elderly in nursing homes are there because they have not taken their medication properly; did not eat properly while they were at home; and have sustained a fall where they were not discovered for hours and sometimes days. If the residential care program had been utilized nursing home placement would not have been necessary.

Most of the time residential care facilities are not utilized because the general public is not aware of any service other than nursing homes. If they are aware of the services they are not utilized because there is no funding available. They cannot afford the private pay rates so they choose nursing home placement because of medicaid reimbursement.

In Arkansas the residential care program is one where we discourage the institutional appearance, our aim is to see that each licensed facility provides a safe home like atmosphere, that the residents are provided personal care i.e. assistance in bathing and dressing and reminded to take their medication and provided three nutritious meals daily.

We presently have 95 licensed facilities in Arkansas, of those we have approximately 80 that are doing an outstanding job. Approximately 10 are doing an average job and 5 are borderline facilities. Our greatest concern with those 5 is the physical plant, these facilities house predominately mentally ill clients, who tend to be more destructive than the clients in other facilities.

One of the biggest problems for the residential care facilities is being identified as a "boarding home" or "nursing home". Until the general public is educated as to what a residential care facility is and until there is some kind of regulation for "boarding homes" the residential care facilities will have problems being identified as a legitimate step in a continuum of care for the elderly.

I am including a copy of the regulations for Long Term Residential Care facilities in Arkansas. Over all we are pleased with our regulations even though we plan on making some changes in the very near future, concerning qualifications of the facility managers and clarification of some areas, where we have a conflict because of different interpretations. I feel that the residential care program should receive as much attention from our government for those independent elderly who need some supervision and personal care as does the nursing home patients. There are far more elderly who fall into this classification.

Thank you for you interest in the program, and if I can be of any assistance at any time please let me know.

Sincerely,

Jerry N. Rayburn

Jerry N. Rayburn, Administrator
Residential and Adult Day Care
Office of Long Term Care
(501-682-8468)

JNR/am
enclosure (1)

Item 6

SCOTT'S COMMUNITY RESIDENTIAL FACILITY
2103 First Street, N.W.
Washington, D.C. 20001

Telephone Numbers: (202) 265-5599 or 265-4096

To the Chairman and Committee members of the Senate Special Committee on Aging -- Good Morning.

My name is Mary T. Scott, Past President of the Capitol Association of Community Residential Facilities, Incorporated. I am here today on behalf of the Community Residential Facility Operators in the District of Columbia. I am pleased to have this opportunity to testify before this committee today on Board and Care Facilities Regulations and Standards.

I do not believe most of you know how difficult it is to operate a Community Residential Facility in this day and time, with the very low rates we are paid to provide quality care for our clients.

We, as operators of Community Residential Facilities, do a very good job. We know there are a few bad facilities, but most of us provide the best care our residents have ever received. Our facilities are neat, clean, attractive and some of them are simply beautiful. Our residents receive three good, wholesome, well-balanced meals each day plus snacks and tender loving care.

We are mothers, fathers, sisters, brothers, barbers, nurses, beauticians, social workers, counselors and their transportation to and from, doctors offices, clinics, recreations, etc. Some of us purchased special vans just for transportation for our clients. Community Residential Facility Operators provide 24 hour supervision, this is just to mention a few of the tasks we provide for our residents.

Regardless of the amount of work we do, increases in food prices, repairs, plumbing, insurance, etc. we cannot pass this on to our clients as most businesses do.

We are not even compensated for half the work we perform.

We as operators of Community Residential Facilities provide a most needed and vital service to our residents, not to mention our government.

We have been asked to treat our residents as family in which we have done.

Growing old or tying to survive in this land of plenty is living hell.

Our residents deserve better and so do we. They molded and paved the future for most of us, and made this city what it is today.

We have all spent our life savings doing a good job for our residents and our government. It is time that we are compensated for the work and service we provide. It is time the government assume their responsibilities and care for its most vulnerable population. Just think about the money we have saved the government over the years.

We only receive $ 460.20 per month. If we do a little calculation, that is only $ 15.34 per day. Not even 64 cents per hour, just $ 6,000 per year. This is not even minimum wage. Minimum wage is $ 4.75 per hour.

Nursing homes get at least $ 48,000 per year per client and they do not provide quality care like the Community Residential Facilities. A day care program gets $ 118.00 per day per client and their clients are only there for 3 1/2 to 4 hours with lunch.

If you are able to write up a proposal that the Government and Mental Health Commissioners will accept, then United Way will provide matching funds.

These Community Residential Facilities get $ 15,000 per year per client. This includes funds from Social Security, Supplementary Social Security and private funds. Most of us are unable to write up a beautiful proposal, but we know how to provide quality tender-loving care and all the necessities that our clients need. Most of us provide the very same care as the operators who get the contracts. Contracts are not even mentioned to small operators, but we have to abide by the some strenuous regulations and laws as people with contracts.

I have seven (7) residents. Most homes have from 1 to 4. When we go to the grocery store, our bread, eggs, milk, chicken, hamburger, etc. cost us the same as yours.

In 1985, I replaced all windows in my facility at 2103 First Street, NW, the cost was $ 7,500.00. In 1986, I replaced both upper and lower rear porches. This home improvement cost over $ 1,500.00. I also had a new roof put on at a cost of $ 2,200.00.

Some of the major expenses for 1987 were installation of a new central heating and air condition system that cost over $ 6,000.00. These installations were done for my clients convenience, pleasure and safety. Other expenses were as follows: gas for heating and cooking for $ 1,683.27, electric bill $ 1,134.54, water bill $ 1,152.97, food $ 7,041.58, insurance for Community Residential Facility $ 1,927.00, insurance for van $ 1,362.00, gas for van $ 1,086.31, installation of electric smoke detectors and other electric repairs $ 750.00, mortgage $ 3,666.00, house taxes $ 859.66, laundry bill $ 946.35.

I have been in the red for the last five years. Attached are a listing of expenses for 1987 and my program statement.

The government should be paying for the insurance we have for our clients, such as: fire, theft and personal property damage which is very expensive. I have no problem with malpractice insurance if we were being paid a decent salary.

Due to the escalating prices of utilities, food, extra demands put on us by the Department of Consumer and Regulatory Affairs every time they visit our facility for relicensure, civil infraction laws/fines, lawsuits by resident relatives, and normal day-to-day living, the Community Residential Facility Operators are requesting a pay increase of at least $ 900.00 per month.

I am involved in a lawsuit from a family of one of my former residents who died seven (7) months after leaving my facility. The lawsuit is for $ 3 million dollars plus interest and cost of court for wrongful death of this client. This is an untrue and unjust claim. This is another extra expense for attorney fees and an increase in the rate of my insurance.

In the future we want to be separated in the budget, not lumped with other district/federal government agencies. We would like to have funds set-aside specifically for Community Residential Facilities.

Thank you.

Expenses 1987 - Scott's CRF

1. New roof - $ 2,200.00
2. New heating system & central air conditioning $ 6,000.00
3. New freezer $ 632.81
4. New dish washer $ 500.17
5. Glass for dining room table $ 145.10
6. Gas for heat and cooking $ 1,683.27
7. Water bill $ 1,152.92
8. Electric bill $ 2,134.54
9. Trash removal service $ 480.00
10. Extermination $ 460.00
11. Advertisement $ 350.00
12. Magazines $ 110.00
13. Newspapers $ 134.80
14. Home Box Office $ 269.40
15. Upholstery repairs $ 65.00
16. Vacuum cleaner $ 269.00
17. Licenses for Community Residential Facility $ 7.00
18. Nurses licenses $ 50.00
19. Tax services $ 250.00
20. Laundry bill $ 946.35
21. New grill $ 125.00
22. Insurance for van $ 1,362.00
23. Gas for van $ 1,086.31
24. Tags for van $ 83.00
25. Telephone business $ 375.00

26. House repairs such as paint, etc. $ 400.00
27. Insurance for Community Residential Facility $ 1,977.00
28. Van repairs $ 750.00
29. Installation of electric smoke detectors and other electric repairs $ 750.00
30. Food $ 7,041.58
31. Mortgage payment $ 3,666.00
32. House taxes $ 859.63
33. Mortgage insurance $ 78.55
34. Hazard insurance $ 553.00
35. Doctor bills $ 918.75
36. Medications $ 512.00
37. Personal property tax $ 73.00

SCOTT'S COMMUNITY RESIDENTIAL FACILITY

2103 FIRST STREET, N.W.

WASHINGTON, D.C. 20001

TELEPHONE NUMBERS: (202) 265-5599 OR 265-4096

PROGRAM STATEMENT

Welcome to Scott's Community Residential Facility, Mary T. Scott, Residence Director and Owner.

On behalf of my staff and myself, I welcome you.

Our program is designed to meet all the needs of those entrusted to our care, efficiency and thoughtfulness.

Our facility gives each resident a feeling of security and a sense of well being.

We are dedicated to providing tender loving care, excellent food and a clean and sanitary environment.

My home is centrally heated and air conditioned for your convenience.

My rooms are neat, clean, spacious, with wall-to-wall carpet, smoke detectors in all rooms and two smoke detectors in hallways; battery and electric.

We are centrally located in Washington, D.C.. The metrobus is within one to three blocks from my residence. The metrobus can be used to connect to many forms of transportation, such as the other metrobus lines, the metrorail, the Greyhound/Trailway bus terminal, the Amtrak/Union Station, and the National Airport.

RULES AND REGULATIONS

We must respect each others rights and privileges.

WAKE UP TIME

1. Residents that work wake-up on their own. If found that they are over sleeping, they are awakened by the Residence Director or staff person on duty.
2. Wake-up time for residents who do not work is 6:30 a.m..
3. Bath and oral hygiene daily.
4. Make-up beds and tidy rooms daily if necessary.
5. Come downstairs for breakfast.

MEALS

1. Breakfast served at 6:45 a.m. for working residents.
2. Breakfast served at 8:00 a.m. for non-working residents.
3. Lunch served at 12:30 p.m..
4. Dinner served at 5:00 p.m..

MEDICATIONS

1. Urine test at 7:30 a.m. with assistance for diabetics.
2. For residents on insulin, insulin will be administered around 7:30 a.m. with assistance.
3. All other medications are taken between 6:30 a.m. - 7:45 a.m. with assistance.
4. For residents who receive medication three times a day, the second dose is given between 1:00 p.m. and 2:00 p.m..
5. Bed time medications are taken at 8:30 p.m..

PROGRAMS

1. Residents who attend programs prepare for departure between hours of 9:00 a.m. and 9:45 a.m..
2. Residents are scheduled to arrive at program at 10:00 a.m. and return between the hours of 1:00 p.m. - 3:00 p.m..
3. Residents in work therapy return between the hours of 11:30 a.m. and 4:15 p.m..
4. After this, they prepare for dinner.
5. After 5:00 p.m., free time on their own: watch TV, play games, take walks, visit family or whatever until 9:00 p.m..
6. Night time medication is taken at 8:30 p.m.. If out after 9:00 p.m., residents must notify Residence Director and give his/her whereabouts and time expected to return. Residents should call Residence Director when departing for home.

SMOKING

1. No smoking in rooms.

2. Smoking in designated areas only.
3. Designated smoking areas are: recreation room downstairs, porch and other places outside.
4. If residents do not abide by these rules, he/she will be asked to leave.

TOWEL AND LINEN CHANGE

1. Linen and towel change every Wednesday or as often as needed.

VISTING HOURS

1. Everyday from 9:00 a.m. - 9:00 p.m., if resident is not in program. All other times must be approved ahead of time.
2. Resident may visit family as often as family permits: overnight, week-ends, vacations, also annual trip to Wilson, North Carolina; however if residents prefer not to attend the family outing they are allowed to stay with their family members until my return, all patients prefer attending the outing.

ADMISSION POLICIES

1. Physical examination thirty (30) days prior to admission.
2. Every resident must have his/her own doctor or a clinic to attend.
3. Every resident must see a physician at least once a year including X-rays.
4. No cooking.
5. No alcoholic beverages.
6. No visiting after 9:00 p.m..
7. No vulgarity and/or disruptive behavior will be allowed.
8. Smoking only in designated areas.

RATES OF PAY

1. Our fees and charges are negotiable and are based on a monthly payment to us by the resident or his/her relative.
2. The rates of pay per month are based on client's ability to pay and level of care needed.
3. Rates of pay will be on a escalating scale with minimum cost being the rate the SSI and District pay for a resident to live in a Community Residential Facility. At present the rate is $ 460.20 per month.

DISCHARGE POLICY

1. If resident's condition improves enough to need less restricted living environment.

2. Notification of resident relative and physician when his/her condition deteriorates enough to need higher level of care.

3. If resident causes confusion, and does not follow house rules.

4. Discharge request by family and approved by doctor.

5. Not paying his/her bill on time. Counseling will be provided the first and second time the patient does not pay his/her bill. If the patient does not pay his/her bill, a letter will be sent asking him/her to find another place to live.

6. In non-emergency situations, I will give the client advance oral and written notice of discharge.

7. If it is an emergency, I will try to contact District of Columbia Long Term Care Ombudsman Legal Counsel for the Elderly - Ms. Ann Hart or Mrs. Beverly Bryant, 1909 K Street, N.W., Washington, D.C. 20049, Telephone number (202) 662-4933.

AGAIN, WELCOME TO SCOTT'S COMMUNITY RESIDENTIAL FACILITY. I HOPE YOUR STAY WILL BE A PLEASANT AND REWARDING ONE.

I HAVE READ THE RULES AND REGULATIONS AND UNDERSTAND THEM AND AGREE TO ABIDE BY THEM.

SIGNATURE_____

DATE_____