

**ASSISTED LIVING:
A CHOICE FOR
THE FUTURE**

CONTENTS

EXECUTIVE SUMMARY	1
THE REPORT	2
DEFINITIONS	6
THE FRAMEWORK FOR CHANGE	
SERVICES	12
HOUSING	17
QUALITY	21
NEXT STEPS: ACTION	30
ATTACHMENTS	31

The Intra-Governmental Council on Long Term Care would like to thank the members of the Assisted Living Work Group; its Chairperson, Ann Torregrossa, and the many, many other persons who contributed their time, their knowledge, and their opinions, which led to the development of this report. It took two and a half years and a great deal of compromise on the part of stakeholders representing consumers, providers, purchasers, advocates and state government officials to reach this point. The Work Group began with a diversity of experiences and expectations. There were different goals, different ideas of what to accomplish, and different time frames for accomplishing the goals. There is no one who is totally satisfied with everything in this report. It's a tribute to all those involved that they continued to come and work even though they frequently didn't get what they wanted. It ended with a general consensus on what needs to be done in the future. This report and its recommendations are the result.

The Council would also like to thank those citizens who volunteered their time to share their thoughts, concerns, and ideas as part of the twelve structured discussion groups held across the Commonwealth. This report has been enriched and informed by the opinions shared at those sessions.

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EXECUTIVE SUMMARY

BACKGROUND

Assisted Living is a rapidly growing long term care alternative across the nation. Assisted living is a combination of housing and services as needed. It is extremely popular with the general public because it allows people to age in place, maintain their independence and exercise decision making and personal choice. Many states use it as an alternative to more expensive nursing home care.

In Pennsylvania, assisted living is a private market phenomenon. There is no uniform assisted living definition; no required public oversight of entities which hold themselves out as providing assisted living, although many are licensed as personal care homes; no uniform way of assuring assisted living quality; and limited access to assisted living except for persons with higher incomes.

In December 1996, the Pennsylvania Intra-Governmental Council on Long Term Care (Council) convened an Assisted Living Work Group to define assisted living for Pennsylvania. The Work Group met its goal by developing an assisted living philosophy and definitions of 'assisted living residence' and 'assisted living services,' which were accepted by the Council in April 1997.

The Council then charged the Work Group with developing recommendations on the regulatory, funding, and quality assurance issues related to assisted living. The Work Group reported back to the Council in June 1998 with a report containing 58 recommendations related to these issues. The Council accepted the report and asked the Work Group to specifically work on what authority is needed to implement the recommendations, how to fund the recommendations, and how to implement the quality assurance recommendations.

The Work Group reported back to the Council in December 1998 with additional and more specific recommendations on how to implement and fund the recommendations.

This report incorporates all previous reports and recommendations from the Assisted Living Work Group into a final report from the Council.

WHAT IS BEING RECOMMENDED?

- A definition of assisted living residences and assisted living services, along with a statement of philosophy.
- Housing and services should be separated for purposes of assuring quality and funding. Services should be available based on functional need.
- Assure quality in assisted living by making the consumer the primary determiner of quality.
- Ways to make assisted living available to Pennsylvanians of all income levels.
- Implementation of the recommendations through administrative and legislative action.

THE FRAMEWORK FOR CHANGE

SERVICES

- Use Medicaid waivers to pay for services.
- Allow Medicaid waiver services in assisted living residences and personal care homes and domiciliary care homes.
- Develop a new fundable service called cognitive support service to allow persons with Alzheimer's and other cognitive problems to live in a residence of their choice.
- Increase the numbers of home and community-based services through a phased process by adding 3,000 slots in FY 99/2000, and 5,000 in FY 00/01, with a goal of 36,000 Medicaid-funded home and community based service slots by the year 2010.
- Use state funding for services to persons with incomes between 300-400% of SSI and institute cost sharing and sliding fee scales.
- Require prompt mandatory assessment for determining functional eligibility for all publicly funded long term care services.

HOUSING

- Use public funding to assist people receiving home and community based services to pay for housing if it avoids institutionalization and is cost effective.
- Set aside 10 - 12% of Low Income Tax Credits for assisted living.
- Establish a dedicated loan fund to allow existing personal care homes and nursing facilities to convert to assisted living.

QUALITY

- Facilities which meet the definition of assisted living residences must be licensed. No place shall call itself an assisted living residence unless it is licensed.
- Entities which coordinate or manage and directly provide assisted living services for payment should be licensed or subject to funding requirements if there isn't any existing oversight, supervision or regulation.
- In situations where existing assisted living services have some form of public oversight, either licensure, certification or funding requirements they will not require additional oversight.
- Quality assurance factors should be monitored through a combination of governmental regulations, funding requirements, accreditation, and by the consumer on their own.
- Explore alternatives such as making assisted living a limited medicaid state plan service if it is cost effective and avoids unnecessary institutionalization.
- Use quality indicators to increase quality of life outcomes.
- New statutory authority is needed to move forward on key elements of assisted living and this should be done through a comprehensive legislative package.

WHY DO WE NEED TO DO THIS NOW?

- The number of persons needing long term care and services will continue to grow.
- The cost of nursing facility care has been increasing at a rate of approximately 7% a year. By the year 2010 the Medicaid Nursing Facility expenditure per person will be \$63,759 vs. \$22,144 in 1997 if this trend continues.
- If we continue to rely on Nursing Facilities for long term care, our costs will increase from \$1.9 billion in 1997 to \$5.8 billion in 2010 – tripling the long term care budget in 13 years.

CONCLUSION

- Consumers continue to say that the three things they most want are to stay independent and live at home as long as possible; respect and dignity for the individual; and a choice of options for long term care and services. To do nothing ignores what consumers want.
- Modeling the various options clearly shows that the Commonwealth can save money by paying for assisted living rather than continuing to rely exclusively on nursing facility care.

THE REPORT

TODAY'S PRIMARY OPTION, NURSING FACILITIES, COST THE MOST . . .

Currently, nursing facilities are the primary publicly funded option for Pennsylvanians needing long term care and services. That option is the most expensive, and can cost \$120 a day in some areas of the Commonwealth, or more than \$40,000 a year. An estimated 746,000 of Pennsylvanians need long term care, yet most don't have the health care coverage, insurance and/or savings to pay for the care they need.

About 80 percent of state Medicare beneficiaries have gross annual family incomes of under \$25,000. Medicare, the primary health care coverage for older Americans, pays only for a very limited number of skilled nursing days.

. . . AND ARE THE LEAST DESIRED

Pennsylvanians view nursing facilities as homes of last resort. In focus groups conducted across the Commonwealth by the Intra-Governmental Council on Long Term Care, residents of all ages and stations were asked to talk about what they would want if they had long term care needs. We found great consensus: Pennsylvanians want to remain in their own homes for as long as possible. When the time comes that they can no longer be safely supported there, they want to live in the kinds of residences in which their independence, dignity and ability to make choices are maintained. Nursing facilities are seen as the last place to find these conditions.

BUT, ASSISTED LIVING IS UNDEFINED, UNREGULATED AND UNAFFORDABLE FOR MANY

The marketplace is responding on its own without state government oversight to the desire of Pennsylvanians for alternatives to nursing facility care. Establishments that call themselves "assisted living" are springing up across the Commonwealth. Assisted living which offers a combination of housing and services on an as needed basis, are becoming extremely popular with the general public because they allow people to age in place, maintain their independence and exercise decision making and personal choice.

In Pennsylvania, assisted living is a private market phenomenon. There is no uniform assisted living definition; no required public oversight of entities which hold themselves out as providing assisted living, although most are licensed as personal care homes; no uniform way of assuring assisted living quality; and limited access to assisted living except for persons with higher incomes

"Pennsylvania used a major state Lottery to fund some home and community based programs, but even with these dollars added, the nursing home (sic) still account for 93.39% of all public long term care dollars."

April 1999
State LTC Profiles Report

"... the more telling message was that while there is a place for nursing facilities, no one really wants to be in one. The participants also found it extremely frustrating that nursing facilities are often the only choice."

February 1999
Structured Discussion Groups

"Currently, the assisted living industry is predominantly funded by private resources and is licensed and regulated by the states."

April 26, 1999
GAO Report

DEFINITIONS

DEFINING A BETTER WAY

The Assisted Living Work Group of the Intra-Governmental Council on Long Term Care has spent more than two years examining and analyzing the above conditions. The Work Group has studied the experience of other states, listened to focus groups of Pennsylvanians, assembled cost projections, and formulated recommendations for the development of assisted living in Pennsylvania.

The 41-member Work Group was comprised of all stakeholders: consumers, including representatives of persons needing long term care and services due to age and/or disabilities; the assisted living, personal care home and nursing facility industry; state legislative staff; government officials; providers of home and community-based services; housing developers; advocates, and others.

- September 1996 - Council Report to Governor Ridge recommends that stakeholders be convened to define assisted living.
- December 1996 - Assisted Living Work Group (Work Group) is convened to define assisted living.
- April 1997 - Work Group presents a philosophy statement, and definitions of assisted living services to the Council. Council accepts philosophy and definitions and requests the Work Group to work on quality assurance, regulatory and funding issues.
- June 1998 - Work Group reports back to Council with 58 recommendations. Report accepted by the Council and the Work Group is asked to work on how to implement the quality assurance, and cost/funding recommendations and determine what authority is needed to implement the recommendation.
- Nov/Dec 1998 - Twelve structured discussion groups are held around the Commonwealth to educate and obtain feedback about assisted living.
- December 1998 - Council accepts Report from the Work Group with some changes. Council requests that a final Report be developed and that the state Departments discuss the Report and provide feedback to the Council.

This report is a consensus document. Every member of the Work Group both rigorously advocated their viewpoint and made concessions. The result is a document that all the members said they could live with. Early in the process, accord was reached on the need for definitions of “Assisted Living Services” and “Assisted Living Residences,” and the adoption of an “Assisted Living Philosophy.” Indeed, the commitment of all stakeholders to the following definitions has strengthened over the course of two years’ work.

WHY THE NEED FOR DEFINITIONS

It is essential that when consumers seek, or when government helps pay for, components of Assisted Living, that there be common definitions.

Assisted Living Services cover two principal categories: assistance with activities of daily living (ADLs), which include bathing, toileting, dressing, etc., and instrumental activities of daily living (IADLs), such as needing a third party to be responsible for paying bills and securing food and clothing. Alzheimer’s and other debilitating diseases and conditions may require a combination of services. Regardless of the intensity of help needed, services should be provided in an atmosphere that permits each resident to live as independently as possible. The Work Group defined Assisted Living services as:

ASSISTED LIVING SERVICES

Assisted Living services are a combination of supportive services, and personalized assistance services designed to respond to individual needs of those who need assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Most Pennsylvanians want to age in place in their own homes. Sometimes, that becomes no longer appropriate or possible. When living at home puts a person’s health and very life at risk, a change of housing may be necessary, no matter how reluctantly accepted. For some, the solution may be moving to a small apartment; for others, it may mean housing that offers 24-hour-a-day assisted living services. For residents who would be at great risk remaining in their own homes, assisted living residences can delay and even preclude the need for nursing facility

The Work Group reviewed definitions of assisted living from 31 other states, six national organizations and five Pennsylvania organizations.

“States which emphasize consumers use terms such as independence, dignity, privacy, decision-making and autonomy as a foundation of their policy. Statutes, licensing regulations, and Medicaid requirements in 22 states, up from 15 states in 1996, contain a statement of their philosophy of assisted living.”

April 28, 1999
Testimony to U.S. Senate
Special Committee on Aging
Hearing

care. The Work Group defines an Assisted Living Residence as:

ASSISTED LIVING RESIDENCE

An assisted living residence :

- is a residential setting that offers, provides and/or coordinates a combination of personal care services, 24-hour supervision and assistance (scheduled and unscheduled) activities, and/or health related services;
- has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences;
- has an organizational mission, service programs, and a physical environment designed to maximize residents’ dignity, autonomy, privacy, and independence;
- encourages family and community involvement; and
- will disclose services offered, provided, and/or coordinated and the costs thereof.

In focus groups and through surveys Pennsylvanians told us emphatically that the spirit in which long term care services are provided is as important as the physical surroundings in which they are offered. They insisted that their long term care be accorded in a manner that supports their independence, dignity and choice. The following was developed and approved by the Work Group.

STATEMENT OF PHILOSOPHY

- Assisted Living starts with a philosophy that encourages and supports individuals to live independently.
- Assisted Living provides individuals privacy and dignity.
- Assisted Living supports the consumer living in the residential environment of their choice.

- **Assisted Living promotes integration of individuals into the community and participation in the mainstream of activities.**

- **Assisted Living maximizes consumer choice to promote and support his or her changing needs and preferences. Consumer choice includes the right of individuals to make decisions about their own care and to take responsibility for certain risks that may result from their decisions, consistent with the individual’s capacity to make decisions and the provider’s exercise of prudent risk management through negotiated risk agreements.**

DEFINING THE CONSUMER

An ongoing issue is how to encourage consumers’ decision making and promote risk sharing for a growing number of consumers with Alzheimer’s or other related dementias. Who should determine when a consumer can no longer make decisions for themselves? Who should make decisions for the consumers no longer able to do so for themselves? The following was agreed on as a way to begin addressing this issue.

For the purposes of this report, consumers are defined as persons who purchase assisted living services on their own behalf. The definition also includes persons who need assistance from responsible persons or family members in purchasing services due to cognitive impairment severe enough to interfere with functioning and persons who freely request such assistance. (Such requests should not be interpreted as modifying a consumer’s right to make his or her own legal decisions without appropriate legal action pursuant to protective services or guardianship.)

IS THE CHANGE TO ASSISTED LIVING AFFORDABLE?

We know what Pennsylvanians want, and we have consensus on how to define assisted living services, assisted living residence, and a philosophy. The question is , “Can we afford to do it?” The answer of the Work Group is YES. In fact, we cannot afford not to do it.

One in 10 persons over age 65 and nearly half of those 85 and over have Alzheimer’s disease.

More than 50% of all nursing home residents are victims of Alzheimer’s disease or related disorder.

National Alzheimer’s Association

By the year 2010 Medicaid nursing facility expenditures per person will be \$63,759 vs \$22,144 in 1977.

Between 1995 - 2010 the over 85 year old population will increase by 143,980 persons.

Persons 80-89 years of age represent 41.9% of the nursing facility population.

- Pennsylvania’s continued reliance on expensive nursing facilities for most of its publicly-funded long term care will cause the Commonwealth’s long term care budget to double every seven years.
- Our demographics dictate an even greater need for alternatives to our state’s long term care services system. Residents most needing long term care (over age 85) comprise the fastest growing segment of our population, and Pennsylvania has the second highest percentage of population over age 65.
- Most other states that have opted to use public funding to provide alternatives to nursing facility care have designed systems which allow their citizens to remain at home, age in place, and maintain their independence, dignity and choice of residence for as long as possible. They have saved money as a result.

MEETING THE CLEAR AND PRESENT CHALLENGE AND FUTURE NEEDS

This report proposes a clear win-win response. By designing a long term care system that provides consumers more choices and allows them to age in place, Pennsylvania will (1) respond to the desires of its citizens, while (2) providing public funding for long term care services to many more residents. By doing so, the Commonwealth will meet the clear and present challenge presented by our state’s changing demographics.

Pennsylvania has both the opportunity and the mandate to transform its long term care system. Consider:

- A long term care system that provides primarily one publicly-funded option – care in a nursing facility – provides little if any choice. Services must be unbundled and available a la carte. A person should be able to get just those services that are needed and wanted at a location of choice, whether that place be a private residence, an assisted living residence, or a personal care home.
- A system that offers alternatives will give residents the opportunity to determine their own care, and accept the risk of those choices. Risk is the trade-off for independence and choice. In a nursing facility, the organization

assumes all responsibility for the care of residents. By choosing to remain at home, or live in an assisted living residence, one shares risk with the provider of services.

- Consumers needing long term care services must be given the choice to age in place in their homes and in their communities rather than in nursing facilities. Consumers and families want those choices, and they generate more sustainable costs for consumers, families and taxpayers in the long run.
- Education is a key component of a long term care system offering options beyond nursing facility care. Pennsylvanians need to be informed as to their choices regarding long term care services.

“Above all else, people want to have control and input into the key decisions which will dramatically impact their life. We also heard that control without choices is a hollow victory.”

Fall 1997
Structured Discussion Groups

THE FRAMEWORK FOR CHANGE

ASSISTED LIVING SERVICES

Pennsylvania must take advantage of the flexibility permitted in federal Medicaid funding to offer a broad menu of services (including cognitive support) to allow Pennsylvanians to remain in their own homes. Rather than expanding nursing facilities, most additional future public resources should be targeted for home and community-based care, including assisted living.

Albeit limited, Pennsylvania has begun to use this flexibility to provide public funding for assisted living services in a person's home. Experience shows the cost to be about half of what it would otherwise be to pay for the same person in a nursing facility. Thus, by targeting increased long term care resources for assisted living services, Pennsylvania can serve twice as many people in the community as in a nursing facility.

Financial eligibility for these services is currently 300 percent of the SSI (over \$1,500 per month), a level that will allow a large percentage of Pennsylvanians to qualify.

This approach is already working elsewhere: 38 other states are using this federal flexibility to help their residents gain access to assisted living services in assisted living residences. All states employ this flexible method to finance care in a consumer's home or apartment.

Several general principles comprise the basis of the following recommendations for changing Pennsylvania's system. They are:

- Principle 1.** State government funds should be the payer of last resort.
- Principle 2.** Generally, it is preferable to use state funds to match federal funds rather than use state funds by themselves.
- Principle 3.** In general, payment should be unbundled. Unbundled means that housing is separate from services, that payment for each is separate, that persons are not required to take services that are not needed, and that residents don't have to be dependant on their landlord for life sustaining needs.
- Principle 4.** Whether public payment should be in the form of subsidies to the individual or payments to the provider will depend upon the particular circumstances but the preference is to empower the individual whenever possible.

Comparison of total public

costs per day per person:

- ◆ *Nursing Facility \$101.12*
- ◆ *Home and Community Based Services (Aging Waiver) \$50.24*

USE OF MEDICAID WAIVERS

Recommendations S-1

- Medicaid (Medical Assistance, MA) should be used to pay for services.

Recommendation S-2

- The state supplement to SSI or Medicaid funding for services, should be related to functional need, not residence. A person could receive assisted living services in their own home, a Domiciliary Care home, personal care home, or an assisted living residence as defined by statute.

Recommendation S-3

- The Medicaid waivers should be expanded statewide to cover services in assisted living residences and personal care homes. After the Commonwealth addresses the estate recovery issue, consideration should be given to requiring eligible persons to use services funded by the waiver rather than by the Lottery.

Recommendations S-4

- Home and community based services (Medicaid waiver) should be available to eligible individuals residing in personal care homes (until personal care homes and assisted living combine) under the following conditions:
 1. the services are not required to be provided by the personal care home provider;
 2. the consumer has choice of provider of services;
 3. there are actually multiple providers available and not a default situation;
 4. an outside agency is responsible for assessment and care management (especially for persons with cognitive impairments);
 5. the waiver services supplement and do not supplant the personal care home services;
 6. appropriate oversight and protections are in place, including an assessment of the capability to provide adequate care to individuals requiring higher acuity needs, including those with cognitive impairments.

“By early 1999, 32 states covered service in residential settings, either assisted living or board and care licensing category, through Medicaid.”

April 1999
Testimony to U.S. Senate Special
Committee on Aging Hearing

Study of personal care homes in 1995 found;

- ◆ *18.9% of residents suffered from dementia*
- ◆ *21% used a walker*
- ◆ *12.7% used a cane*
- ◆ *9% used a wheel chair*

“Many state leaders are concerned about affordability. Several surveys have found that over 50% of the assisted living facilities charge a monthly fee for private pay residents that is \$2,000 a month or lower. That is very affordable for state Medicaid programs and well below the cost of a nursing home.”

April 1999
Testimony to U.S. Senate Special
Committee on Aging Hearing

In Pennsylvania FY 1997-1998 on average

- ◆ *76,312 persons received Medicaid funded nursing facility care*
- ◆ *1,746 received Medicaid funded home and community based waiver services.*

“Pennsylvania has the worst commitment of any state to home and community based services. It spends the lowest percent of Medicaid home and community based services dollars in the nation, with 99.44% of Medicaid dollars going to nursing homes.”

April 1999
State LTC Profiles Report

7. only personal care homes which provide consumer choice, independence, privacy, and dignity to its residents.

Recommendation S-5

- Publicly funded assisted living services should include those presently covered under the home and community based services (HCBS) waiver plus cognitive support service (see Attachment 1 for Definition and Waiver Provider Standards). These services should be available to qualifying consumers based on the assessment/care plan for the individual consumer, but capped by the waiver program cost limits.

Recommendation S-6

By FY 2010, 36,000 Medicaid funded HCBS slots should be available. This would represent 40% of the need for nursing facility care. In order to allow adequate time for the development of the services, the following phase-in schedule is suggested:

- For FY 99/2000 Pennsylvania should seek Health Care Finance Administration (HCFA) approval to have 3,000 additional Medicaid funded HCBS slots, in addition to state-funded slots for persons with incomes between 300 and 400% of SSI.
- For FY 2000/01 Pennsylvania should seek HCFA approval to have 5,000 Medicaid funded HCBS in addition to state funded slots for persons with incomes between 300 and 400% of SSI.
- For FY 2001/2002 Pennsylvania should seek HCFA approval to have 7,000 Medicaid funded HCBS in addition to state funded slots for persons with incomes between 300 and 400% of SSI.
- For FY 2002/2003 Pennsylvania should seek HCFA approval to have 9,000 Medicaid funded HCBS in addition to state funded slots for persons with incomes between 300 and 400% of SSI.

IS THERE A BETTER WAY?

Recommendation S-7

- The number of persons eligible for MA funded services should be expanded. The first phase would use the nursing facility eligibility standard to maximize federal funding through Medicaid. The Department of Public Welfare should look at what flexibility it has to modify its present definition to maximize the number of people who could qualify under this functional definition if it avoids unnecessary institutionalization and it is cost effective. These persons would all qualify for HCBS assisted living services.

Recommendation S-8

- Many residents with high functional needs often end up in nursing homes simply because they are unable to receive adequate services in the community. A pilot project would test whether providing broader functional eligibility for assisted living helps keep in their own homes consumers whose only current option is nursing facility care, when they pay privately until they become Medicaid eligible. It should be less expensive to share the costs of services in the community for these consumers with state money, than to end up paying more for them in a nursing facility at a later date. Budgeted amounts should be set in diverse settings across the state with an evaluation component to determine the cost effectiveness of these diversion strategies.

Recommendation S-9

- At some point in the future, Commonwealth agencies should assess whether it is cost-effective to add a narrowly defined assisted living service to a targeted eligible population as a Medicaid state plan service not restricted to nursing home eligibles. To gain more effective cost data and experience to permit government to properly define and cost this recommendation, we

“States typically use the home and community based services waiver (1915(c)) to finance care, however regular state plan services are used in five states.”

April 1999
Testimony to U.S. Senate Special
Committee on Aging Hearing

recommend implementation of Recommendations S-7 and S-8.

Recommendation S-10

- Medicaid HCBS services should be used to pay for those meeting the functional eligibility criteria who have incomes below 300% of SSI. Where it is cost effective and avoids unnecessary institutionalization, use state funded slots to pay for those meeting the functional eligibility who have incomes between 300%-400% of the SSI level. Consumers with incomes above 400% of the SSI level could probably pay for their own assisted living services where it is cost-effective and avoids unnecessary institutionalization. Cost sharing and sliding fee scales should be used for those with incomes between 300% - 400% of the SSI level.

In 1997-1998 the OPTIONS program assessed:

- ◆ 51,884 persons for nursing facility eligibility
- ◆ 36,267 were referred to nursing facilities
- ◆ 15,620 were referred for home and community based services

ASSESSMENTS AND ELIGIBILITY DETERMINATION

Recommendation S-11

- A public agency, such as the Area Agency on Aging assessment unit, should be the gatekeeper for determining functional eligibility for all publicly funded long term care services, in order to assure consistent assessment and to assure that consumers are given choices for long term care services.

Recommendation S-12

- Mandatory assessment of any person who may need publicly funded nursing facility care should be done quickly and consumers needing assisted living services should be given a choice of receiving those services in the location of their choice or in a nursing facility, if they qualify for nursing facilities services. If HCBS services are chosen, consumers should be given assistance to promptly put the services in place. In the absence of expedient alternatives, families will turn to nursing facilities to meet the need.

Recommendation S-13

- Medical Assistance eligibility needs to be promptly determined. If HCBS cannot be put in place quickly, families will turn to nursing facilities to meet the need.

REGULATIONS AND MODEL PROJECTS

Recommendation S-14

(Note: Text in **brackets []** and **bold-faced** is to be deleted, text in **bold face without brackets** is to be added.)

- That the Department of Health's proposed definition of "skilled or intermediate nursing care" {Pennsylvania Bulletin, Vol. 27, No. 29, July 19, 1997, p. 3620} be amended as follows: "Skilled or intermediate nursing care." Professionally supervised nursing care and related medical and other health services provided **directly or under the direction of the licensed entity** for a period exceeding 24 hours to an individual not in need of hospitalization, but whose needs **[are above the level of room and board and]** can only be met in a long term care nursing facility on an inpatient basis because of **[age,]** illness, disease, injury, convalescence or physical or mental infirmity. The term includes the provision of inpatient services that are needed on a daily basis by the resident, ordered by and provided under the direction of a physician, and which require the skills of professional personnel, such as, registered nurses, licensed practical nurses, physical therapists, occupational therapists, speech pathologists, or audiologists."

Recommendation S-15

- That the Commonwealth pursue innovative assisted living systems, e.g., the Robert Wood Johnson demonstration cash and counseling project, and other models that may be available.

HOUSING

Current Medicaid rules on housing need to be made consistent. Medicaid pays for food and shelter costs of a person in a hospital, in a community residence for persons with MH/MR, and in a nursing facility. However, Medicaid does not pay for housing or assisted living residences for residents deemed to need nursing facility care, but who want to remain at home.

Currently, Medicaid lacks the federal flexibility to provide housing cost supplements as an alternative to more expensive nursing facility placement. Most states that are helping lower-income residents with housing costs in assisted living resi-

dences do so because it meets residents' health care needs and personal wishes at a lower cost to the state.

We recommend the targeted use of state funds where it is more cost effective for the Commonwealth to assist consumers with housing costs, and avoid a more costly nursing facility placement.

Low Income Tax Credits should be allocated to help provide housing specifically intended for persons needing assisted living services as a more efficient alternative to additional nursing home beds in locations where suitable facilities are lacking.

The following is recommended:

Recommendation H-1

- As a way of maximizing resources, public funding should be available to assist people receiving HCBS to pay for housing, including their own home if it 1.) is necessary to avoid institutionalization, and 2.) is cost effective as compared to institutional care. The public funding for housing should be linked to a functional need for services as determined by an objective individual assessment. The maximum individual public funding available for this purpose should be adjusted for regional housing costs and should be based on some criteria such as PHFA's regional standards for operating costs for low income housing. Because the number of people potentially eligible for such public funding would be limited by the number of HCBS slots applied for by DPW and approved by HCFA, the costs could be carefully monitored and controlled.

HOW TO PAY

Recommendation H-2

- The Low Income Housing Tax Credit Program should be used to help develop assisted living residences. Specifically, it has the advantages of:
 - *reducing costs* – it may eliminate an interest-bearing layer of financing which the project would otherwise have to obtain. This means that the project's debt service obligations will be reduced and, in turn, project costs will be lowered. This can result in more dollars for operations.

Modeling done by the Work Group showed that Pennsylvania could save \$1 million a year for every 100 SSI recipients receiving home and community based services in an assisted living residence as opposed to a nursing facility, even with a housing supplement.

- *restriction on rents charged* – the rents charged to low and moderate income tenants will be restricted, since a qualified low-income project must restrict rent in low income units to 20% of 50% or 40% of 60% of area median income.
- *restriction as to low-income use of the facility* – the assisted living facility that is developed must be held for low-income use for a minimum of 15 years.
- *creation of residential rental properties* – must be structured to qualify as a residential rental property. By definition it is not available to hospitals or nursing homes. Instead, residents must be able to live independently with limited assistance in the activities of daily living.
- *shares assisted living philosophy* – the apartment units created must be separate and distinct from other living units; have a separate kitchen and bath, and each unit should have a lockable door. Recreational and laundry facilities should be available for all of the residents without additional fees.

Recommendation H-3

- Low Income Tax Credits can be used to cover a large amount of the development costs of an assisted living residence for low and moderate-income residents. For the next four years, the Governor/PHFA should set aside enough tax credits to permit the development of 200 assisted living residence units a year (10%-12% of the available tax credits). Each year, Pennsylvania Housing Finance Agency, in consultation with the Department of Public Welfare, the Pennsylvania Department of Aging, and the Department of Community and Economic Development should issue an RFP for assisted living residence units for persons eligible for the HCBS to see what the market can produce using local Community Development Block Grant funds, foundation and other funding. The project should especially address renovations of nursing homes and hospitals to take beds off-line and replace them with assisted living residences and assisted living services.

Recommendation H-4

- We encourage the use of other existing financing programs for the development of assisted living residences.

“When asked what single condition was most important, more than three times the number of participants selected private room over a locked door or private bath.”

February 1999
Structured Discussion Group

They include:

- Community Development Block Grant funds
- Act 137 (Optional County Affordable Housing) funds
- Neighborhood Assistance Program
- Penn Homes Program
- Home Investments Partnerships Program
- Federal Home Loan Bank Affordable Housing Program
- Mortgage insurance programs

Recommendation H-5

- If public funds are used to develop new or modify existing units to become assisted living residences, those units should be designed and built to allow each person to live independently. Each should include:
 - a self-contained unit, capable of being locked by the resident;
 - sharing by the resident’s choice;
 - its own bathroom (toilet, sink, shower or bath);
 - its own kitchenette or food preparation area (counter space, microwave, refrigerator, cabinet and sink) or other food provision determined by the choice of the resident;
 - a sleeping area;
 - a living area;

Adjustments may be necessary for some units for persons who are significantly cognitively impaired.

Recommendation H-6

- A funding resource such as guaranteed loans should be made available (potentially through the Department of Community and Economic Development) to assist with renovations that would not be large enough to warrant using low income housing tax credits. Some examples include:
 - renovations needed to convert personal care homes and senior housing projects to assisted living;
 - upgrading of fire safety features;
 - other physical plant renovations;
 - renovations to upgrade hospitals, nursing facilities, personal care homes, and housing developments to provide assisted living residences and assisted living services.

A condition of receiving the funding should include some process for insuring that people desiring such housing who are receiving HCBS receive priority. The marketing of the units should include those agencies for people who are eligible for HCBS.

Recommendation H-7

- A revolving loan fund should be established to assist persons to modify their personal residences if the lack of doing so is the primary reason for their needing to go to a nursing facility.

Recommendation H-8

- Both the need to obtain financing to *build* the facility and the need to obtain financing to *maintain* the facility must be kept in mind so that additional financial burdens are not imposed on the low and moderate income residents. Developers must be able to secure conventional market financing and also capital from private investors. This can be done by providing an environment that will encourage partnerships between housing developers and those experienced in health care.

“At the same time as interest in assisted living has grown, concerns about quality of care and consumer protection in assisted living have been raised in recent media accounts and other reports.”

April 1999
GAO Report

QUALITY

Consumers must be the primary determiners of quality. Persons attending the Intra-Governmental Council on Long Term Care focus group sessions adamantly concurred on the need for a consumer-oriented approach that helps assure quality in assisted living. Services need to be consumer directed and consumers must be given a viable selection of needed quality services.

Quality needs to be assured through a combination of licensure and public funding standards. The Council has not recommended detailed regulations or other quality measures because the specifics of assisted living services and assisted living residences in Pennsylvania have not been finalized.

**Key Messages
Regulation and
Quality of Care**

- ◆ *Regulation by itself can not ensure quality.*
- ◆ *Quality should be driven by the consumer, with minimal practical regulation serving as a starting point.*
- ◆ *Direct consumer feedback on care and services is critical.*
- ◆ *The nursing facility model for quality is a failure and assisted living should not follow that path.*

February 1999
Structured Discussion Groups

The following principles guided the development of the recommendations:

- Principle 1. All parties involved in assisted living need to know that they are entering unfamiliar terrain. This is true for the consumer, the provider, the regulator, the funder, and legislators. Acceptance and accommodation of a learning curve are necessary.
- Principle 2. We need a new quality assurance paradigm which includes the consumer as the primary determiner of quality. We believe that assisted living represents a major shift in the way that long term care is provided. Assisted living moves from a model of the provider being responsible for the resident to the concept of shared risk between the consumer and the provider. The current models of quality assurance are based on the provider being responsible and generally focus on regulations and requirements for the provider. We believe that regulations are necessary, but constitute only one component of the quality assurance picture.
- Principle 3. Quality assurance is the responsibility of all parties in the assisted living picture - not just providers or consumers. We have identified five major players or components responsible for assuring quality in assisted living in Pennsylvania. They are: **consumers, providers, payers, regulators, and legislators.**

We looked at what we think are appropriate roles for each of these in a comprehensive quality assurance structure.
- Principle 4. Each of the five groups should be educated about the assisted living philosophy. Education of each is essential to insure that there is a commonly understood philosophy which will promote an integrated quality assurance structure rather than five groups each moving in different directions. Assisted living represents different assumptions, different responsibilities, different expectations of each of the components.

- Principle 5. To effectively carry out its respective role, each of the five components has a responsibility to obtain and utilize information from the other parts of the Quality Assurance system to carry out its respective role. Ideally each will share with the other, subject to safeguards for confidentiality. In practice it will probably be necessary for each to request and identify specifically what information it needs from the others. An example - licensing staff should obtain information about an assisted living residence from providers and funding sources as well as from consumers and organizations established to assist consumers; e.g., ombudsman and client assistance programs.
- Principle 6. A corollary to the above is that each of the five parties responsible for assuring quality has a responsibility to share information and to communicate changes, new requirements and expectations with the other four parties.
- Principle 7. Consumers should be provided with comparative information on assisted living facilities, including cost and quality, to assist in making an informed choice.

The following is recommended:

LICENSING

Recommendation Q-1

- An assisted living residence should be licensed and regulated by the Commonwealth.

Recommendation Q-2

- No place shall call itself an assisted living residence unless it is licensed.

Recommendation Q-3

- An entity not already licensed that both coordinates and provides assisted living services for payment should be licensed. If public funds are used, then appropriate standards should be in place. State designated agency programs, guardians, and family members should be excluded from this proposal. State designated agencies,

“Twenty two states have existing licensing regulations using the term assisted living, up from 15 in the previous study.”

June 1998
State Assisted Living Policy

such as Area Agencies on Aging and Centers for Independent Living as well as guardians already have some form of oversight, supervision, and regulation.

THE REGULATORY SYSTEM

Recommendation Q-4

- Provide adequate funding for the licensing and regulatory functions. In order to assess outcome measurements including consumer satisfaction, and to communicate directly with consumers of the service, licensing and regulating may be more labor-intensive than in some other types of long term services or residences.

Recommendation Q-5

- Provide funding to adequately train licensing staff.

Recommendation Q-6

- Regulators should spend more of their scarce resources on assisted living residences and services that have problems meeting the basic standards and regulations, and less on those that have demonstrated capacity and performance.

Recommendation Q-7.

- The regulations must be enforceable. The period of time given to providers who have problems and the time allowed for corrections should be shortened. When a provider is not providing quality care, has been notified and given time to correct the situation and does not, the regulators should be given the authority to protect the consumers with an array of tools. These tools should include suspension or revocation of a license to operate a business or practice a profession and appointing temporary management when appropriate. In order to enforce the standards and regulations, there needs to be alternative placements for residents.

Recommendation Q-8.

- While it is appropriate to use a range of penalties that include punitive fines and penalties to assure minimum performance, it may also be useful to use non-monetary incentives to reward exemplary performance.

Recommendation Q-9

- Regulators should separate the roles of licensing and technical assistance. Primary responsibility for technical assistance is with the residence or services or with the industry.

Recommendation Q-10

- The regulatory system should adopt appropriate safeguards for confidentiality.

Recommendation Q-11

- Regulators need to assure appropriate training for those with consultative, monitoring or enforcement responsibilities.

Recommendation Q-12

- Licensing personnel and other parts of the quality assurance system should coordinate to share information as it relates to health and safety and residents' rights, subject to proprietary or confidential information; e.g., consumers, funders.

CONSUMER RIGHTS AND RESPONSIBILITIES
Recommendation Q-13

- Consumers should know that they have both formal and informal ways to address their grievances.

Recommendation Q-14

- Consumers who choose assisted living should know that they are assuming responsibilities different than other long term care alternatives. Responsibility for choosing services, billing for services and housing may be separated. They also bear responsibility to voice any concern and obtain information through the regulatory process.

Recommendation Q-15

- There needs to be a continuum of opportunities for consumers to give input and receive feedback - from positive comments to negative complaints and from an informal to and including a formal complaint process. Resident councils provide one opportunity.

“Consumers want and need an easy to access central source of information, where they can go and get answers to all their questions.”

Fall 1997
Structured Discussion Groups

“Sixteen states have adopted or proposed a negotiated risk process to involve residents in care planning and to respect resident preferences which may pose risk to the resident or other residents.”

June 1998
Mollica

Recommendation Q-16

- That the concept of shared risk, i.e. the mutually agreed to acceptance of risk that is documented, made knowingly and freely, needs to be part of a contractual relationship between consumers and providers. Minimum health and safety requirements may not be waived through a shared risk contract. Consistent with the philosophy of assisted living, providers shall use their best efforts to reach mutually agreeable shared risk arrangements that maximize consumer autonomy.

Recommendation Q-17

- An integral part of any quality assurance plan must include independent third party review. The third party might be an ombudsman or a client assistance model. Whatever form it takes will require public funding. The focus here is on the consumer. There could also be third party review of providers, such as a peer review or accreditation process.

Recommendation Q-18

- There needs to be a right of individuals to seek legal redress for grievances, and a forum, apart from the regulatory process, in which to do it. This could take any number of forms; e.g., grievance procedures, contract enforcement, etc. Questions about the order in which these or other methods of legal redress must be used, or if there are any conditions to the use of a particular method, have not yet been addressed. (The Work Group could not reach agreement on whether consumers should be able to privately enforce regulations.)

PROVIDER RESPONSIBILITIES

Recomendation Q-19

- The provider community needs to be educated that assisted living must assure consumer choice, independence, privacy and dignity. Any licensing regulations developed must reflect the assisted living philosophy. Providers are responsible to ensure adequate training and education on health and safety requirements, quality assurance, consumers’ rights, contractual rights and responsibilities and a statement of philosophy for assisted living for everyone they employ or report to;

e.g., administrators and staff, governing boards, consultants and others.

Recommendation Q-20

- Providers have a responsibility to facilitate and create adequate formal and informal opportunities for feedback from consumers, families, advocacy organizations, funders and regulators.

Recommendation Q-21

- Providers have a duty in accordance with principles of good faith and fair dealing to negotiate contracts with consumers and carry out their contractual obligations.

Recommendation Q-22

- Providers should provide accurate information to consumers and regulators.

Recommendation Q-23

- Providers have a responsibility to know about applicable federal, state and local laws and to understand them.

Recommendation Q-24

- Providers are responsible to access technical assistance and to improve performance problems identified by the regulators or through their internal quality improvement efforts.

MEASUREMENT, SUBSIDIES, AND AMENDMENTS

Recommendation Q-25

- We recommend the use of quality indicators to measure quality of life outcomes, including autonomy, independence, and dignity. We need to participate with those organizations nationally that are working on development of quality indicators. Consistent with the Assisted Living Quality Coalition we believe that these indicators must:
 - account for differences among settings and residents;
 - be thorough enough to instill confidence but;
 - not be too cumbersome or expensive to administer.

“Rather than relying exclusively on process compliance surveys, the Coalition urges states to experiment with ways to focus the monitoring process on defined quality outcomes.”

August 1998
Assisted Living Quality Coalition

Recommendation Q-26

- If public subsidies are provided to the individual for assisted living residences and services, funders should provide fair market subsidies. “Fair market subsidy” is determined by timely surveys of geographically appropriate markets. To be timely, surveys should be done annually and must take into account the consumers assessed assisted living needs. Subsidies should be at a level to assure access by those Pennsylvanians for whom subsidies will be paid. The geographical size of the market should reflect actual living patterns and should not be so big as to distort the subsidies. For example, surveying a market as big as all five southeastern counties would create a subsidy that does not reflect the true market in both Philadelphia and Chester counties.

Recommendation Q-27

- Generally, whatever information is available to the regulatory agencies should be available to consumers, providers, legislators and the general public. Safeguards must be in place regarding proprietary and confidential information and to protect the rights of the consumer.

Recommendation Q-28

(Note: Text in **brackets []** and **bold-faced** is to be deleted, text in **bold face without brackets** is to be added.)

- The definition of “long term care nursing facility” in Chapter 8 of the Health Care Facilities Act (35 P.S. § 448.802a) should be amended as follows:
 “Long term care nursing facility.” A facility that provides either skilled or intermediate nursing care or both levels of care to two or more patients, who are unrelated to the licensee, for a period exceeding 24 hours. Intermediate care facilities exclusively for the mentally retarded, commonly called ICF/MR or **ICF/ORC**, **personal care homes, Domiciliary Care homes and/or assisted living residences as defined by statute**, shall not be considered long term care nursing facilities for the purpose of this act [**and shall be licensed by the Department of Public Welfare**].

Recommendation Q-29

(Note: Text in **brackets []** and **bold-faced** is to be deleted, text in **bold face without brackets** is to be added.)

- The definition of “personal care home” in Act 185 and

Chapter 2620 (P.S. 55 § 2620.3) should be amended as follows: “PCH” - personal care home - A premise in which food, shelter and personal assistance or supervision are provided for a period exceeding 24 hours for four or more adults who are not relatives of the operator, who do not require the services in **[or of]** a licensed long-term care **nursing** facility, but who do require assistance or supervision in matters such as dressing, bathing, diet, financial management, evacuation of a residence in the event of an emergency or medication prescribed for self-administration.”

Recommendation Q-30

- Maintain the broad medical necessity definition to maximize coverage of services under the state Medicaid plan for those needing ongoing care. (Note: Text in **bold face is to be added.**)

Medical Necessity – Determinations of medical necessity for covered care and services, whether made on a prior authorization, concurrent, or post-utilization basis, shall be in writing, be compensable under MA, and be based on the following standards. The plan shall base its determination on medical information provided by **the individual**, the individual’s family and the primary care practitioner, as well as any other providers, programs, and agencies that have evaluated the individual. Medical necessity determinations must be made by qualified and trained providers. Satisfaction of any one of the following standards will result in authorization of the service:

- the service or benefit will, or is reasonably expected to, prevent the onset of an illness, condition, or disability.
- the service or benefit will, or is reasonably expected to, reduce or ameliorate the physical, mental, or developmental effects of an illness, injury, or disability.
- the service or benefit will assist the individual to achieve or maintain functional capacity in performing daily activities, taking into account both the functional capacity of the individual and those functional capacities that are appropriate for individuals of the same age.

THE NEXT STEP: ACTION

The Council calls upon the legislative and administrative branches of our state government to move ahead to transform the way long term care is provided in our Commonwealth. The recommendations reflect the best efforts of the Intra-Governmental Council on Long Term Care and the Assisted Living Work Group. Pennsylvanians want these changes, there is consensus among the stakeholders that they need to be implemented, and there is a financial imperative to do so. The following action agenda is proposed by the Council:

Recommendation NS-1

- That the final report be presented to the Governor and the Legislature.

Recommendation NS-2

- That a comprehensive legislative package should promptly be developed to implement the Council's recommendations.

Recommendation NS-3

- That a work plan be developed by the Departments to implement the recommendations in this report.

Recommendation NS-4

- That the Council continue public education to support the implementation of the assisted living recommendations (consumers, providers, legislators, policymakers, and other stakeholders).

ATTACHMENT 1

COGNITIVE SUPPORT SERVICES STANDARDS

Cognitive Support Services are provided to individuals who have memory impairments and other cognitive problems that significantly interfere with their ability to carry out activities of daily living without assistance and who require supervision, monitoring, and programming be available to them twenty four hours a day seven days a week in order to reside safely in the setting of their choice and otherwise qualify for home and community-based waivers.

Providers shall only be reimbursed for Cognitive Support Services when services are provided as part of a comprehensive plan of care that adequately assesses risk sharing by the individual consumer (and, where appropriate, his/her family member or responsible caregiver). Services may be provided either in the private residence of the consumer, in an adult day care center, or in an appropriate community residential facility licensed by the State.

Provision of Cognitive Support Services will not affect a provider's ability to collect SSI. Reimbursement for room and board costs will not be made under the Cognitive Support Service category. However, providers must maintain both secure indoor and outdoor walking areas and have any necessary approvals from applicable regulatory authorities.

Environments should maximize consumer autonomy, safety, and quality of life as part of the comprehensive plan of care.

DESCRIPTION OF SERVICES

Cognitive Support Services include assessment, service planning, ongoing monitoring, personal care assistance, health support services, and a full range of dementia-capable activity programming, and crisis management, maintaining the "capacity of provider service" on demand, twenty-four hours a day, when required by a consumer in a licensed personal care home (assisted living residence) or domiciliary care home.

B. AAA RESPONSIBILITY

1. ASSESSMENT AND ONGOING MONITORING

- a. Residents with cognitive impairment should have an appropriate assessment.
- b. The health status of residents with cognitive impairment should be monitored and assessed routinely, with a focus on the prevention of unnecessary co-morbidities.

- c. A cognitive impairment assessment and service planning system should produce programming that maximizes independence and focuses on strengths and abilities.

2. **COORDINATION OF SERVICES**

Services should be carefully coordinated to maximize routine levels of care and to provide quality of life indicators for the consumer with cognitive impairment.

C. **ROLE OF FAMILY**

All service planning activities should incorporate the consumer and family member/responsible caregiver as much as possible.

D. **QUALIFICATIONS TO BE A WAIVER PROVIDER**

- 1. Cognitive Support Service providers must be educated in the mission and purpose of services to individuals with cognitive impairments and receive appropriate training in the following areas:
 - ◆ Consumer rights
 - ◆ Fire and Safety
 - ◆ First Aid/CPR
 - ◆ Basic Nutrition/Medication Training
 - ◆ Program Philosophy/Mission
 - ◆ Assessment and reporting of health problems
 - ◆ Understanding of Dementia: causes, symptoms, treatments, and management techniques
 - ◆ Changes in condition and appropriate responses
 - ◆ Dementia-capable Activity Programming
 - ◆ Communication skills and management of behavioral challenges
 - ◆ Mental health issues
 - ◆ Reporting laws regarding abuse and neglect
- 2. For all providers, an orientation program related to dementia may include:
 - ◆ Normal aging – cognitive, psychological, and functional abilities of older persons.
 - ◆ Definition and diagnosis of dementia, description of reversible and irreversible causes, and explanations of differences between dementia, delirium and depression.

- ◆ Explanation of dementia and related disorders, progression, stages and individual variability.
- ◆ Communications techniques.
- ◆ Description of behavioral symptoms of dementia and how to approach residents when they display challenging behaviors
- ◆ The role of personality, culture, and environmental factors in behavioral symptoms and dementia care.
- ◆ The assisted living residence philosophy of dementia care, including mission statement, goals policies and procedures.
- ◆ Working with family members.
- ◆ Community based resources for residents with dementia and their families.
- ◆ Team building and stress reduction for assisted living residence staff.

3. RECORDS AND DOCUMENTATION

- a. Provider must maintain progress notes detailing incidents involving consumers, including instances when the individual is not at base line status (i.e., changes in behavior, disrupted sleep cycle and eating problems).
- b. At a minimum, monthly monitoring of consumer vitals must be charted.
- c. A quarterly “service plan” must establish individualized outcome oriented objectives for the consumer and specify strategies that will be implemented to achieve objectives. It is recognized that in some instances, maintenance of the “status quo” is an appropriate consumer outcome.

PENNSYLVANIA INTRA-GOVERNMENTAL
COUNCIL ON LONG-TERM CARE
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