



**SPEAKER'S SUMMIT ON  
SENIOR SERVICES**

---

**LONG-TERM CARE**

**FINAL REPORT**

INCLUDING TESTIMONY FROM  
STATE AND REGIONAL SUMMITS AND  
MINNESOTA'S AND MAINE'S LONG-TERM CARE REFORM

**JANUARY 2004 — SPRINGFIELD, ILLINOIS**  
**MICHAEL J. MADIGAN, *SPEAKER***

---

---

## TABLE OF CONTENTS

---

---

	PAGE
MEMORANDUM, SPEAKER MICHAEL J. MADIGAN .....	i
PANELISTS AT STATE SUMMIT MEETING.....	ii
BACKGROUND.....	1
FINDINGS.....	3
PRIMARY RECOMMENDATION .....	4
ADDITIONAL RECOMMENDATIONS .....	9
 <u>ATTACHMENTS</u>	
A: SUMMARY OF TESTIMONY/STATE MEETING.....	17
<u>CHART 1:</u> WHERE PEOPLE RECEIVE SERVICES.....	31
STATE AND MEDICAID SPENDING .....	32
<u>CHART 2:</u> NURSING FACILITY EXPENDITURES .....	32
NURSING FACILITY DISCHARGES TO ASSISTED LIVING .....	32
NURSING FACILITY DISCHARGES TO HOME.....	33
NURSING FACILITY LENGTH OF STAY.....	33
 B: SUMMARY OF TESTIMONY/REGIONAL MEETINGS .....	 67
 C: JAMES VARNNESS POWER POINT PRESENTATION	
 D: CHRISTINE GIANOPOLOUS POWER POINT PRESENTATION	

---

## PANELISTS AT STATE SUMMIT MEETING

---

### GOVERNMENT OFFICIALS / ISSUE EXPERTS

DONNA FOLKEMER, *Program Manager*

FORUM FOR STATE HEALTH POLICY LEADERSHIP,  
NATIONAL CONFERENCE OF STATE LEGISLATURES

CHRISTINE GIANOPOULOS, *Director*

BUREAU OF ELDER & ADULT SERVICES,  
DEPARTMENT OF HUMAN SERVICES, MAINE

JAMES VARPNESS, *Director*

AGING & ADULT SERVICES DIVISION,  
DEPARTMENT OF HUMAN SERVICES, MINNESOTA

LOUANNER PETERS, *Deputy Chief of Staff*

SOCIAL SERVICES, OFFICE OF THE GOVERNOR

RAY THRELKELD, *Chief*

HEALTH CARE BUREAU, OFFICE OF THE ATTORNEY GENERAL

MICHAEL GELDER, *Deputy Director*

ILLINOIS DEPARTMENT ON AGING

RICK DEES, *Chief*

BUREAU OF LONG TERM CARE,  
ILLINOIS DEPARTMENT OF PUBLIC HEALTH

ANNE MARIE MURPHY, *Medicaid Director*

ILLINOIS DEPARTMENT OF PUBLIC AID

MARTA SAYEED, *Home Services Bureau Chief*

ILLINOIS DEPARTMENT OF HUMAN SERVICES

MARTHA HOLTSTEIN, *Project Manager*

HEALTH AND MEDICINE POLICY RESEARCH GROUP

### SENIOR GROUPS/COMMUNITY REPRESENTATIVES

DONNA GINTHER

AARP

MIKE O'DONNELL

ILLINOIS ASSOCIATION OF AREA AGENCIES ON AGING

JULIE SAMPSON

CITIZEN ACTION

MATT KEPPLER, *Public Policy Director*

ALZHEIMER'S ASSOCIATION

WENDY MELTZER

ILLINOIS CITIZENS FOR BETTER CARE

STEVE PITTMAN

ILLINOIS ALLIANCE FOR RETIRED AMERICANS

SHIRLEY KELLOM, *Steward*

SEIU LOCAL 880

RODERICK S. BASHIR, *Deputy Trustee  
Vice President*

SEIU LOCAL 4  
INDUSTRIAL AND ALLIED DIVISION OF SEIU LOCAL 1

**NURSING HOME REPRESENTATIVES**

WILLIAM L. KEMPINERS, *Executive Director* ILLINOIS HEALTH CARE ASSOCIATION  
TERRENCE SULLIVAN, *Executive Director* ILLINOIS COUNCIL ON LONG TERM CARE  
STEPHEN NUSSBAUM, *Administrator* WINCHESTER HOUSE, REPRESENTING LIFE SERVICES NETWORK

**COMMUNITY BASED CARE AND HOME HEALTH CARE REPRESENTATIVES**

KELLY SCHLEICH, *President* ILLINOIS ADULT DAY SERVICES ASSOCIATION  
KAREN CRIPPS, *Area Director of Adult Day Services* ADDUS HEALTH CARE  
ANN DERRICK, *RN, MSN, Vice President* ILLINOIS HOMECARE COUNCIL BOARD OF DIRECTORS  
KAREN TAMELY, *Director of Programs* ACCESS LIVING  
ANN FORD, *Executive Director* ILLINOIS NETWORK OF CENTERS FOR INDEPENDENT LIVING

**MEMBERS OF THE ILLINOIS HOUSE OF REPRESENTATIVES**

Representative JACK MCGUIRE, *Co-chair* (D-JOLIET)  
Representative DAN REITZ, *Co-chair* (D-STEELEVILLE)  
Representative JOE LYONS (D-CHICAGO)  
Representative MARLOW COLVIN (D-CHICAGO)  
Representative ELIZABETH COULSON (*excused absence*) (R-GLENVIEW)  
Representative ROSEMARY MULLIGAN (*excused absence*) (R-DES PLAINES)  
Representative SUZANNE BASSI (R-PALATINE)

**STAFF**

KURT DEWEESE OFFICE OF THE SPEAKER, RESEARCH/APPROPRIATIONS  
CECELIA HYLAK-REINHOLTZ OFFICE OF THE SPEAKER, RESEARCH/APPROPRIATIONS  
AMANDA CHESLEY HOUSE MINORITY LEADER, RESEARCH/APPROPRIATIONS

INTEROFFICE

# MEMORANDUM



to: Illinois House of Representatives  
from: Michael J. Madigan, *Speaker*  
re: **Speaker's Summit on Senior Services — Long Term Care**

---

Attached is the **SUMMIT ON SENIOR SERVICES — LONG TERM CARE** report, which is the second of three topics recommended for special consideration by this 93<sup>rd</sup> General Assembly.

This report includes findings, recommendations, and summaries of the testimony provided at the Regional and State Summit Meetings conducted this past summer and fall. The report is intended as a comprehensive record and reference to assist in the further evaluation and implementation of long term care system reforms in Illinois.

The recommendations are proposals submitted by the various witnesses, but have not been endorsed by any particular member(s) of the Illinois House of Representatives. The recommendations are presented for further analysis during the upcoming 2004 legislative session. It must be noted, however, that a broad, extraordinary consensus of regional and state summit participants indicated a need for system reform. Health experts, providers and consumers of care, service organizations, advocacy groups, and other interested parties agreed on many of the elements of a reform agenda. This consensus should contribute to the successful development of a major legislative initiative.

I appreciate your active participation in this process through the regional and state summit meetings; especially the directors of aging programs in Maine and Minnesota for sharing their expertise.

I also thank Representative Jack McGuire and Representative Dan Reitz for chairing the final meeting, and Representatives Joe Lyons, Marlow Colvin, and Suzanne Bassi for their participation.

Finally, I commend all of the people who appeared at the regional and state summit meetings for their interest and contributions. The entire process was educational and productive in terms of ideas and recommendations to help effect meaningful system reform. I hope this interest and involvement will continue as we move forward.

---

## BACKGROUND

---

Long-term care of the elderly poses the greatest challenge for national and state governments in terms of meeting the demand for services that enable individuals and families to maintain independence. As the primary payer and regulator of long-term care, states must make a concerted effort to meet this responsibility. Illinois must take the initiative to provide the best possible care for its citizens.

A recent report to Congress by the U.S. Department of Human Services highlighted the following points about the demand for long term care in this country:

- In 2000, there were approximately 13 million Americans — including children, working age adults with disabilities and the elderly — who needed long-term care.
- By 2050, the total number of individuals in need of long-term care services will double, increasing to 27 million, with the aging of the baby boomer generation being the most significant factor contributing to the demand.
- Over the next 50 years, the number of elderly individuals is expected to more than double, increasing from approximately 8 million to 19 million.
- Working age adults with disabilities needing long-term care will also increase from around 5 million in 2000 to about 8 million in 2050. Many of these individuals will need specialized assistance to return or remain in their communities, as well as to return to work.
- According to the Department of Human Services report, 13 million Americans received long-term care services in community-based settings and 2 million Americans received long-term care services in institutional settings in 2000.

A decision by the U.S. Supreme Court (Olmstead v. L.C.) requires that services be provided in the most integrated setting appropriate to the individual--which in many cases are home and community-based care settings. As the number of elderly individuals using either nursing facilities, alternative residential care facilities such as assisted living facilities, or home care services is expected to double over the next 50 years, the task of serving this growing population is going to be more complicated.

Illinois must develop a comprehensive long-term care strategy to guide future policies and procedures in meeting the increasing demand for services.

A Long-Term Care Summit was conducted as the 2nd stage of a Summit on Senior Services announced in January 2003 by the Speaker of the Illinois House of Representatives, Michael J. Madigan. The purpose of the summit was to discuss key issues confronting the elderly. The 1<sup>st</sup> stage held in the spring of 2003 focused on prescription drug relief. That stage helped craft what today is the state's prescription drug buying club through which all seniors can get substantial discounts on their medications. One initiative was implemented January 1, 2004.

This 2nd stage of the summit focused on “Long-Term Care.” It consisted of 30 regional hearings conducted this past summer and a culminating state meeting in Springfield on October 7, 2003. Testimony was received from senior citizens, senior service organizations, senior advocacy groups, care providers, payers of care, state agencies and other health experts regarding the availability of services in Illinois and the need for additional programs and resources, as well as recommendations for system reform. Witnesses were asked to address the following topics:

- NEED: Determining the types and levels of care required to meet demand. Inventory existing services. Estimate future needs.
- CONSUMER CHOICE: Enabling consumers to actively participate in care decisions. Balancing cost, access and quality.
- WORKFORCE: Ensuring the availability of a trained staff.
- INFORMAL CARE GIVING: Strengthening family and in-home care giving.
- QUALITY ASSURANCE: Performance review of state regulation and quality assurance programs.
- GOVERNANCE: Making program and service administration more effective.
- FINANCE: Ensuring consumer choice and quality.

Information gathered at the regional hearings was summarized and is included as an attachment to this report (Attachment B).

Many of the organizations, agencies and some individuals who participated in the regional meetings were represented at the state meeting in Springfield. Two special keynote speakers were also invited from other states that have already been involved in the aggressive reform of the long-term care systems. The directors of senior programs in Maine and Minnesota shared their success stories as a possible guide to Illinois’ reform. The testimony of these experts and other participants is also attached to this report (Attachment A).

---

## FINDINGS

---

There was repeated and consistent testimony at both the regional and state meetings affirming that Illinois' long-term care system is sorely in need of reform.

There is substantial agreement regarding the goals and objectives for achieving reform.

Presentations by the Illinois Department on Aging and Association of Area Agencies on Aging, the AARP-Illinois, the Health & Medicine Policy Research Group, nursing home trade associations and other long-term care providers, as well as health care advocacy organizations, included several specific recommendations that provide a framework for comprehensive reform, which are included in summaries of the regional and state meetings (Attachments A and B).

The directors of senior programs in Maine and Minnesota demonstrated the success of reform strategies that can serve as models for restructuring the existing long-term care system in Illinois. Summaries of their presentations are also included (Attachment A).

The directors of aging programs in Maine and Minnesota reported that the most critical factors in their success were the leadership of the Governor and the General Assembly in the development of a strategic reform plan, and the cooperation of each, together with all other interested parties, in shaping and carrying out the plan. The historic priority and preference of the existing systems for institutional care could not have been broken without that leadership and cooperation.

In addition to other specific recommendations, the Illinois Department on Aging submitted a LONG-TERM CARE REFORM PROPOSAL on November 30, 2003, that generally embodies recommendations included in much of the other testimony. This proposal was not originally delivered at the state meeting in October, but was subsequently drafted and transmitted to the Speaker's office. This proposal provides an important framework that could be adopted by the Governor and General Assembly as a basis for strategic planning to reform the existing long-term care system. The fact that this proposal was been submitted at this time, in relation to the testimony presented at the Speaker's Summit on Long Term Care, signals an unprecedented interest and willingness of the Department on Aging to be an active participant in system reform. The department's proposal is inserted below in its entirety as a primary recommendation.

In addition to the proposal of the Department on Aging, the participation of nursing home trade associations, other providers of long-term care services, area agencies on aging, and advocacy organizations demonstrates a shared interest and commitment to system reform. Their proposals for reform are listed below as "Additional Recommendations."



---

---

## PRIMARY RECOMMENDATION

---

---

### **ILLINOIS DEPARTMENT ON AGING — LONG-TERM CARE REFORM PROPOSAL**

Several states have successfully redirected state spending to help seniors receive the care they need, where they want it, cost effectively. These states have diverted elderly nursing home residents from premature nursing home placement and helped many transition back to the community where they receive high quality care in residential settings. Consistent with the Olmstead Supreme Court decree actual and predicted nursing home spending follows the individual to the community to enhance and expand home and community based service options.

This proposal is based on several fiscal, demographic, social, legal, and political realities:

- No substantial new state or federal funding is immediately available.
- Service expansions and enhancements must be financed from existing spending or new federal or philanthropic funds.
- The fastest growing population group is adults over age 85 who will require significant support during their extended lifetimes.
- Despite increasingly high public expenditures, families continue to provide the vast majority of care for frail and disabled individuals and feel squeezed by pressures to care for their own families as well as aging parents and relatives and disconnected from services and programs that may help.
- There is wide dissatisfaction with currently limited amount and scope of services, access procedures, qualification requirements, and funding levels.
- Seniors nearly universally prefer to spend their final years living at home, with family, or in housing settings that offer privacy, flexibility, and control of schedule.
- Federal law, defined by the Supreme Court's Olmstead decree, requires states to offer services to support those with disabilities, including frail elderly, in the most community-integrated settings possible.
- Payment rates to providers should cover the costs of delivering high quality services and assure adequate wages and benefits for their employees.

### **LONG-TERM CARE REFORM COMPONENTS**

This proposal attempts to address the broad array of funding, financing, administration, and service delivery options to fully meet the needs of elderly who might otherwise be placed prematurely in a nursing home.

EXPAND AND ENHANCE SERVICES AVAILABLE TO SENIORS IN THE COMMUNITY.

- Establish comprehensive case coordination to cover all long-term care options for all elderly throughout the state.
- Provide services that enhance family caregiving.

Research identifies the following as key comprehensive support services aimed at serving highly impaired seniors in their communities:

- ≡ Home delivered meals;
  - ≡ 24-hour emergency alert systems that include temperature monitoring, preventive health and medication reminders;
  - ≡ Respite care and counseling that flexibly serves caregivers' needs;
  - ≡ Transportation, including assisted and mass transit where feasible;
  - ≡ Caregiver advocacy and counseling; and
  - ≡ Home modifications.
- Increase the array of services and the maximum amount of care for which frail elderly are entitled.

This is necessary to assure that clients have a choice in how best to meet their needs and to assure that care is available early mornings, evenings, weekends and holidays as needed to maintain independent living.

- Adjust payment rates to providers of services to assure adequate supply of quality home and community based services.

Current payment rates and methodologies contribute to the lack of critical services in inner city and rural areas.

- Provide consumer-directed service options.

Over the last 10 years, states have experimented with programs that increase the control clients have over their home and community based care. The closer relationship between the clients, their informal caregivers, and paid workers lead to better client outcomes and improved job satisfaction.

ASSIST NURSING HOME RESIDENTS WHO EXPRESS A DESIRE TO LEAVE THE HOME TO MOVE TO MORE INDEPENDENT HOUSING.

- The keystone to the financial feasibility of reforming long term care at this time is the ability to apply the funding now targeted to those in nursing homes to serve those who prefer to return to the community.
- Studies document that up to 25% of nursing home residents do not need and prefer to live in community-based settings. Thousands of Illinois nursing home residents report to their nursing homes their desire to return to the community.
- Aggressive programs in other states have succeeded in transitioning residents back to community settings who would otherwise have lived the rest of their lives in an institution.

ENCOURAGE NURSING HOMES TO CONVERT STRUCTURES AND ADOPT PROGRESSIVE PRACTICES TO ACCOMMODATE CURRENT NEEDS OF FRAIL AND DISABLED RESIDENTS.

To continue to play a prominent role in the future of the long-term care system, nursing homes should be encouraged to convert excess capacity to:

- Single bed rooms;
- Assisted living;
- Adult day services; and
- Recreation and rehabilitation care enhancements.

Pioneer practices, successfully implemented in other states and of great interest to many nursing homes in Illinois, recognize resident needs and desires and offer clients greater control over their daily routines.

EXPAND COMPREHENSIVE DELIVERY SYSTEMS THAT INTEGRATE ACUTE AND CHRONIC CARE AND DEMONSTRATE COST SAVINGS COMPARED TO EXISTING FEE-FOR-SERVICE MODELS.

Despite highly complex medical needs, very few medical providers are linked to the social and support delivery system of the aging network. This reduces the effectiveness of treatment, which results in additional medical costs and deterioration clients' conditions often leading to premature nursing home placement. Illinois should consider development and expansion of nationally successful programs such as Program for All-Inclusive Care for the Elderly (PACE), Social HMOs, and encourage other comprehensive delivery models, such as community health centers, to serve more frail elderly.

DEVELOP COORDINATED INFORMATION, REFERRAL, AND ENTRY RESOURCES FOR ALL LONG-TERM CARE SERVICES AVAILABLE IN A COMMUNITY.

To assure that family members have access to accurate, timely, and appropriate information the state must:

- Significantly improve access to information available from existing telephone hotlines, assuring access during days, evenings, and weekends.
- Integrate services available from Area Agencies on Aging with other designated entry points.
- Increase use of automated programs to ascertain benefits and eligibility information.
- Coordinate eligibility guidelines so clients may complete a single application to determine all programs for which they may qualify.
- Eliminate asset tests for home care where possible to shorten length of application and documentation needed to qualify.

ASSURE PROVIDERS PAY ADEQUATE WAGES FOR QUALITY CARE.

As additional funding becomes available, as described below, Illinois can:

- Increase rates and adopt alternative payment methodologies to increase wages and health benefits for caregivers.

- Target nursing home rate increases to assure quality and adequate staffing.
- Stabilize payments so providers can apply funds to meet current costs, without incurring high debt payments.

ASSURE ADEQUATE SUPPLY OF CAREGIVERS TO MEET FUTURE INCREASED DEMAND FOR SERVICES.

While there are shortages of skilled and semi-skilled workers today the demographics portend massive shortages in the next five to 10 years. The state should implement policies that will attract qualified workers into this industry.

- Assure adequate wages and benefits.
- Establish career ladder for paraprofessionals from unskilled, to semi-skilled to skilled professionals.
- Coordinate efforts with community colleges to assure adequate supply of staff.
- Develop incentives for worker-owned cooperative paraprofessional businesses.
- Consider enhancing responsibilities of nurse aides and homemakers through courses equivalent to those taken by higher-level personnel.
- Consider expanding responsibilities of higher-level nurses to maximize human resource efficiency.

DEVELOP FINANCING MECHANISM TO COVER COSTS OF REFORMED LONG-TERM CARE.

Without new general revenue the state must target existing appropriations to assure seniors are cared for in appropriate settings. Advocacy groups citing the Olmstead decree promote the principle of money following the individual. Applying this principle to frail elderly nursing home residents, the state could dramatically increase services available to seniors who are in or otherwise would be admitted to nursing homes. Studies document that approximately one quarter of all residents do not need the level of care available in nursing homes. This additional funding for home and community based services for residents coming out and staying out of nursing homes would assure adequate, high quality community care to meet their needs and support adequate rates for all providers.

Through the MDS, DPA has identified more than 2,000 of their nursing home residents who want to return home and identify a family member who can help care for them. Federal demonstration programs in other states have found more than 3,000 nursing home residents per year can be cared for at home if creative and aggressive programs are in place to accommodate their residential and personal care needs. Other studies document that up to 25% of nursing home residents do not need that level of care. If Illinois were to establish such a program, it may be possible to relocate as many as 15,000 residents over the next five years. With the money following the individual home, this could generate \$75 million per year for home and community based services.

During this period, the state must identify additional sustainable revenue sources to maintain regular rate increases at end of four-year period. Other elements in a financing plan would include targets to reduce current nursing home placement rates by 10% increase federal

financial participation, as well as aggressive efforts to encourage purchase of long-term care insurance by those who can afford it at younger ages.

DEVELOP ADMINISTRATIVE STRUCTURE TO ASSURE QUALITY, FACILITATE COORDINATION, COOPERATION, AND INTEGRATED SERVICE DELIVERY.

States that have reformed their long term care priorities have routinely established a task force, council, or high level locus of responsibility to lead and report on progress on long-term care reform. To achieve and maintain this rebalancing, Illinois must encourage transfer of funds from institutional to home and community-based service line items during the budgeting and appropriation process to reflect changing client demand. To accomplish this, a governor's office-level task force or mandate to integrate long-term care responsibilities among the various state agencies will be needed.

---

## ADDITIONAL RECOMMENDATIONS

---

The following recommendations were provided by various agencies and organizations and should be considered as part of any comprehensive strategic long-term care plan. The primary source of the specific recommendation is indicated. Duplicate comments by other individuals, groups or organizations are not included, but may be referenced in the attached summaries of the regional and state meetings.

### **LONG-TERM CARE FACILITIES**

- The Illinois nursing home system should be dramatically transformed and strengthened. *Illinois Council on Long Term Care (ICLTC)*
- Nursing homes should evolve from hospital-looking environments to more home-like settings that offer specialty services and private rooms. *Illinois Council on Long Term Care (ICLTC)*
- To improve living environments in the future, nursing homes should be smaller, with residents living in private rooms whenever possible. These environments need to be more "home-like" and stimulating in nature, filled with plants, animals, and children for emotional health; fitness areas for physical health; safe outside parks for persons with dementia; and internet areas and entertainment sections for mental stimulation and family communication. *Illinois Council on Long Term Care (ICLTC)*
- Resident-centered care should be the underlying theme of care in the future, with incentive grants offered to facilities that develop new and innovative practices. *Illinois Council on Long Term Care (ICLTC)*
- Nursing homes can promote resident-centered care, meeting the specific needs of each individual resident. This theme is the hallmark of the Pioneer Movement: designing programs to give residents more day-to-day choices in their life routines, and empower front-line staff to make more care decisions for the residents they serve. Across the nation, nursing home providers are looking beyond the traditional nursing home model to develop new and innovative ways to meet each resident's individual care needs. The kind of management and staffing changes these programs require, however, are often beyond the means of Medicaid nursing homes. The state should sponsor an incentive program for those progressive Medicaid facilities willing to invest in innovative, non-traditional approaches to care. *Illinois Council on Long Term Care (ICLTC)*
- Nursing homes should not be considered housing of last resort, sticking people in them because there is no place else to go. There are 12,000 people with chronic mental illness in Illinois nursing homes and probably half do not need to be there. Most belong in half-way houses, not nursing homes. *Illinois Citizens for Better Care (ICBC)*
- The statewide long-term care occupancy rate currently hovers at about 82% for several reasons. There is a cost to the state for unoccupied beds, as part of the cost of caring for Medicaid residents. It is in the state's interest to provide a financial incentive to providers willing to give up some of these empty beds. Some of these unused beds may be needed

as the “baby boomers” reach their 70s and beyond. Long-term care providers should be given a financial incentive to “bank” at least some of these unoccupied beds for a definite period of time. If there is a need to re-open the beds, the provider would lose a portion of the incentive originally received. Incentives could also be offered to facilities to convert multi-bed rooms into single rooms, which could meet the expectations of seniors and the disabled. Several states have implemented such incentive programs successfully, including Minnesota. *Illinois Health Care Association*

- Because home and community alternatives to nursing homes have expanded, there are nearly 15,000 unused nursing home beds in Illinois. Excess beds equal inefficiency. More beds than people drive up costs. Too many nursing home beds in the system cause unnecessary competition for clients with home and community-based services. Those empty beds are a waste of health care resources and could be converted to modern, quality living space for residents. There should a freeze on the number of new nursing home beds in Illinois. The health facility planning process could issue a moratorium on nursing home beds. *Illinois Council on Long Term Care (ICLTC)*
  
- Additional long-term care facilities should be used to provide other community health and social services. Long-term care facilities already exist in most communities. In many downstate communities the long-term care facility is the only health care entity, and the largest employer. These facilities should be used for services that can be provided in and through these facilities. Capital costs would be far less than building new, freestanding structures. Long-term care facilities operate 24 hours per day, 7 day per week and 365 days per year. They are always staffed, and therefore may be able to provide multiple services to caregivers, seniors and the disabled, such as, but not limited to:
  - ≡ Adult day care
  - ≡ Senior centers
  - ≡ Home health care
  - ≡ Personal response systems monitors
  - ≡ Transportation
  - ≡ Congregate and carry out (special diet) meals
  - ≡ Tele-nurse services
  - ≡ Meals on Wheels
  - ≡ Caregiver support and training services

*Illinois Health Care Association*

- Besides promoting innovation, the state can better meet residents' specific health care needs by certifying nursing facilities based on their specialties. Categories for certification include Alzheimer's disease, stroke, cardiac care, diabetes, skin care and many others. These certifications would help consumers make better nursing home choices, selecting nursing facilities that have the most expertise in the treatment of specific medical conditions. *Illinois Council on Long Term Care (ICLTC)*
  
- It is far more cost effective to revitalize existing nursing homes than construct new ones from scratch. Effective financing and bonding approaches can aid existing facilities to upgrade for modern technology, resident centered equipment, and solar panels and other heating efficiencies. A capital bond program for nursing home should be established to enable facilities to modernize. An equity capital rate could also be established for those homes converting unused beds to quality living space and private bedrooms. Similar "buy back" or conversion programs exist in Minnesota, Iowa, Nebraska, Ohio, and Wisconsin. *Illinois Council on Long Term Care (ICLTC)*

- Low-interest renovation loans through the Health Finance Authority can help transform last century's infrastructure into modern, efficient, people-friendly living environments. *Illinois Council on Long Term Care (ICLTC)*
- Illinois needs to stabilize Medicaid payments and restore the 5.9% Medicaid rate cut made in July 2002.
- To further stabilize payments for providers, at no cost to the state, a Medicaid receivable bond program could be authorized through the Illinois Development Finance Authority. The cost of the bond financing program is borne by the providers, although at an interest rate below commercial markets. *Illinois Council on Long Term Care (ICLTC)*
- Illinois Department of Public Health should immediately implement the quality improvement grants program passed by the 92<sup>nd</sup> General Assembly. Monies for the program come from the fines and penalties paid by facilities for non-compliance. The federal government has already indicated that programs of fines and penalties may be used in creative ways, and this program could be structured to meet the federal requirements. Regulators, advocates, and providers should work together to develop such a program to improve the lives of individuals living in Illinois' nursing homes. The lessons learned through the implementation of these quality initiatives may be transferable to other homes as well. *Illinois Health Care Association*
- Increase the personal needs allowance. Nursing home residents on Medicaid are allowed to keep \$30/month of their own income; everything else goes to the nursing home. This has only been increased \$5 in thirty years. If the personal needs allowance had kept pace with inflation, it would be over \$90/month. What this means is that every Social Security cost-of-living increase residents should be receiving, goes to supplement the Medicaid budget. Residents are left unable to buy shoes, buy a winter coat or underwear, a newspaper, stationery. They cannot afford public transportation, go to McDonald's, or go to a movie. *Illinois Citizens for Better Care (ICBC)*

### **HOME AND COMMUNITY-BASED LONG-TERM CARE SERVICES**

- The state's public policy should be to integrate the disparate home and community-based services into a well-managed continuum of care, from home-care all the way to sub-acute care and rehabilitation services. *Illinois Council on Long Term Care (ICLTC)*
- Build the capacity of our community-based service providers to serve older persons. Increase state grant assistance to the Area Agencies on Aging for community-based services, not just for the information assistance and the home-delivered meals that you're familiar with, but for emergent needs such as medication management. *Area Agencies on Aging*
- Improve community based access to home and community based long term care services through the Illinois Department on Aging, Area Agencies on Aging, their regional service networks, and culturally competent organizations. Include information on the quality and affordability of long term care facilities, housing, and home and community based services; provide information on pre-admission alternatives; utilize the most recent technology for service inventories, benefits eligibility, telephone transfers and internet availability; and increase the visibility of the access system, and the connections between all long term care service providers. *Area Agencies on Aging*



- Expand the range of services available to help seniors live independently, and make those choices real, especially in an environment where people are staying at home with higher and higher acuity levels, by providing State funds for home-delivered meals, transportation and personal emergency response systems under our current Medicaid waiver. Improve access to health care and therapeutic services to help older adults manage chronic illnesses and disabilities more effectively. This was promised in 2000, but never realized because state funds were not appropriated. If the funds had been available, Medicaid reimbursement would have been available for those meals, for those trips, and for those devices that enable people to live at home safely. This should also include empowering and training case managers, so that they can access more complex medical services for the clients who need the help. *Area Agencies on Aging*
- Increase the non-exempt asset limit for the Community Care Program under the Department on Aging from 10,000 to 20,000. *Alzheimer's Association*
- There should be consistent, impartial case management referral agencies, without ties to a particular provider agency, to assess an individual's needs and serve as a resource to clients and families, and to assemble the best array of services in the community to meet a client's needs. *Illinois Council on Long Term Care (ICLTC)*
- Revise the formula used to determine for how many hours of home care the state will pay for people over 65, so it is an honest comparison of home care and nursing home care for each individual. When Illinois initiated its Home/Community Care waiver, the state paid for up to 8 to 10 hours of home care a day for people, because paying for up to that many hours was still cheaper than paying for nursing home care. Now the state pays for maybe 4 hours a day. This isn't because nursing home care has gotten cheaper in comparison to home care. In fact, the opposite is true. It's because the formula has been distorted to artificially lower the number of hours for which people are eligible. This formula, and the assessment process, need to be made honest, again. *Illinois Citizens for Better Care (ICBC)*
- Increase funding for the Adult Day Services reimbursement and transportation line items. Adult daycare is much more than respite. Adult day care plays an important role in the continuum of care, with the potential not only to delay nursing home placement, but to also reduce hospitalization and other acute healthcare costs. *Alzheimer's Association*
- There is a shortage of affordable, accessible housing for seniors and persons with disabilities. Illinois should expand the number and breadth of its existing home-sharing programs, both for full-time residences and for day-time only care, so elderly adults can be cared for while their family members are working. Tie home-sharing into the Assistive Technology project, and existing Medicare funding for occupational therapists, who can do home visits, assess individuals, and make recommendations about what equipment and home adaptations can allow disabled elderly people to stay home safely. *Illinois Citizens for Better Care (ICBC)*
- Convert "202" housing stock to assisted living facilities. The U.S. Department of Housing and Urban Development (HUD) administers the "Section 202 Supportive Housing for the Elderly Program, which provides capital advances to finance the construction and rehabilitation of structures that will serve as supportive housing for very low-income elderly persons and provides rent subsidies for the projects to help make them affordable. The program helps expand the supply of affordable housing with supportive services for the

elderly. It provides low-income elderly with options that allow them to live independently but in an environment that provides support activities such as cleaning, cooking, transportation, etc. State regulations that might prohibit or impede such conversions should be eliminated.  
*AARP*

## **ADMINISTRATION**

- All services, whether home-delivered meals, prescription drug coverage, housing with services, or skilled nursing care, should be accessed through one entry-point and coordinated by a unified case management system. This single-point-of-entry should be consistent community-by-community. A unified case manager system that links a senior with a case manager who remains with them regardless of the type or setting of services they need is imperative. While the Senior Helpline in the Department on Aging does yeoman's work as a phone-based one stop shop, this concept must now be extended to the community level. *AARP*
- Right now individuals spend considerable time just learning how to navigate the system. Many become frustrated and finally enter the system with negative attitudes about how they have been treated. Dealing with health issues of family members is stressful enough without complicating it further. The unification of case management activities would benefit customers, providers, and the state by streamlining the process. Any such process should ensure the fair representation of all types of appropriate services available to the customer, disclosure of the estimated costs of those services, and a clear determination of the personal, health and medical needs of the customer. *Illinois Health Care Association*
- A searchable, user-friendly internet database should be developed to allow seniors and their families to quickly identify what services are available in their area. The web-site should provide families with quality indicators to help them evaluate the various providers. The site should also permit users to access information regarding specific diseases and treatment centers, care techniques, and caregiver support services available in Illinois. *AARP*
- The web-site should include an assessment tool to gauge the needs of the prospective customer, an explanation of the costs of the service options, and a directory of the full range of services available by geographic area. As the site is developed, it could be expanded to include the results of customer satisfaction surveys, quality standards, staffing information, and comments from residents and family members about the service delivered in each setting so that individuals searching the site can get a balanced view. It would be necessary to determine the most appropriate state entity to host and maintain the site, dialog with interested parties about the content of the site and give consideration to what consumer satisfaction information should be contained on the site and the most appropriate method for collecting such data. *Illinois Health Care Association*
- While in some ways the website of the Illinois Department of Public Health regarding nursing homes is helpful, the majority of violations are not posted, despite the legal mandate that they be there. IDPH should either do the work itself, or contract with an entity able to do the job. *Illinois Citizens for Better Care (ICBC)*
- The state could also help consumers make sound health care decisions by developing resident and family customer satisfaction surveys, sharing these results with the public through the internet or by publishing a consumer guide on choosing a nursing home. These

materials should emphasize 3 key areas: the restorative and rehabilitation services that each nursing home provides; the medical specialties of each facility; and the customer satisfaction levels of the individuals served by each home. The Illinois Department of Public Health should work with the provider associations, universities and consumer research experts to develop these resident and family satisfaction surveys. Other states, including Michigan, have successfully developed this type of program. *Illinois Council on Long Term Care (ICLTC)*

## **REGULATION**

- Place a priority on ensuring that there is fair and reasonable oversight of all types of long-term care facilities. State budget cuts and early retirements have significantly depleted the resources of the Illinois Department of Public Health, the agency charged with regularly conducting oversight of licensed long-term care facilities, assisted living establishments, and unlicensed entities. This has stretched existing staff beyond reasonable limits. The majority of the dollars designed to establish a survey unit for assisted living and supportive living facilities was eliminated from the budget approved by the Governor. These circumstances may result in additional stress to the oversight system in Illinois. It is important to ensure that high quality and consistent surveys will be conducted by a team of well-trained surveyors that the elderly and disabled have access to licensed entities, and that unlicensed entities are inspected and, where necessary, closed. This requires the availability of appropriate human and financial resources. *Illinois Health Care Association*
- The current staffing levels for nursing home inspectors and complaint investigators are inadequate to insure the continued safety of nursing home residents. It is imperative that the General Assembly take a closer look. Facility operators have indicated that the situation will become volatile if something does not happen soon. *AARP*
- A more progressive enforcement system administered by the Illinois Department of Public Health should emphasize actual resident care outcomes, rather than the thousands of minor technical mistakes that can happen in every health care setting. The federal government's 30 "sentinel care" outcomes, based on extensive computerized resident assessment data, provides an effective springboard for evaluating the overall quality of care provided in each Illinois nursing home. This allows enforcement agencies to target areas that warrant more intensive investigation, without bogging them in investigations that do not affect resident care. *Illinois Council on Long Term Care (ICLTC)*
- Aggressive enforcement of the assisted living licensure code is important to the viability of the assisted living industry, the financial stability of the facilities, and the health, safety, and well being of the frail elderly residents. *AARP*
- An important aspect of ensuring customer and family satisfaction is the ability to make reasonable complaints and to have those complaints resolved. The current system makes it difficult for an individual to navigate through the complaint process. Currently, the Illinois Departments of Public Health, Human Services and Aging, and the State Police each have complaint hotlines. Individuals contacting these hotlines may not be aware of the appropriate agency to contact when problems arise. Consolidation of these hotlines into a single entity could streamline the process, saving vital time and state resources as well as making the complaint process much easier to access. In addition to a common intake system, it is imperative that common definitions of abuse, neglect and financial exploitation,

common complaint investigation procedures, common definitions of types of complaints, standardized mandated reporter guidelines and standard complaint investigation protocols be established. *Illinois Health Care Association*

- Development of a single complaint intake unit for reporting all forms of elder abuse, neglect, and exploitation regardless of where the senior resides or the relationship of the perpetrator to the victim would reduce the state's costs and eliminate confusion on the part of mandated reporters, residents of facilities, and the public at large. It will also permit the state to embark on a major media campaign to put the single complaint telephone number before the public. Implementation of this recommendation will require common definitions, reporting requirements and procedures, and a common response mechanism. *AARP*
- All providers – facility-based and non-facility-based – should be required to have quality assurance programs in place, and to regularly file quality assurance reports with the state. *Illinois Health Care Association*

## **CAREGIVERS**

- To improve nursing home care in the future, state government must be partners with the nursing home profession to encourage more, better-paid and better-trained staff. *Illinois Council on Long Term Care (ICLTC)*
- The state must begin paying a living wage and providing a health benefit to professional caregivers. State payments for homecare workers and homecare agencies allow for a median wage of only \$6.60 per hour – a wage that assures such workers will live in poverty, regardless of how effectively they work. The work must pay better to build and retain a more professional workforce. The state should abandon the practice of creating poverty-level jobs to provide an essential service to some of the state's most vulnerable populations. The numerous problems affecting the provision of homecare by the state, and denying availability to all who require it, must be addressed systematically. Immediately raise the wages of all Illinois homecare workers to a living wage – \$9.05/hour. Provide health care coverage to all homecare workers employed at least 20 hours/week. *Service Employees International Union-Local 880 (SEIU)*
- A law enacted two years ago required the Illinois Department of Public Health to develop a nurse assistant career ladder program. This program would provide opportunities for nurse aides to receive advanced training, provide better resident care, and enable them to reach higher levels in their professions with increased pay and status. In addition, their training can be used as a bridge towards helping them become nurses. Working with the universities, unions and providers, the state can establish the standards for advanced training. Once standards are agreed upon, the schools, unions and providers can work together to implement the career training that will open up doors of opportunity. *Illinois Council on Long Term Care (ICLTC)*
- Allow long-term care employers to purchase health insurance for their employees through the state employee insurance program. Economies of scale make such insurance less costly than purchasing small group policies and more affordable for financially strapped entities. *Illinois Health Care Association*
- The state should dedicate 20% of its existing nursing scholarship program for nurses who are willing to work in long-term care. The state pays for these scholarships out of existing license fees and fines. *Illinois Council on Long Term Care (ICLTC)*

- Develop a state medication technician program. Through this program, nurse aides receive up to 100 hours of both classroom and clinical training on administering medications. Working under the direct supervision of a licensed nurse, the medication aides would be able to pass out routine medications to residents. This program would not reduce the number of nurses in nursing homes, but free up nurses for more direct bedside treatment. Currently, at least 13 states successfully use medication technicians in nursing homes, including Indiana, Iowa and Wisconsin. *Illinois Council on Long Term Care (ICLTC)*
- Build the capacity of our Illinois families to provide care, such as the Family Caregiver Act, which has passed the Illinois House and is now in the Senate -- Senate Bill 1620. Provide State funding for education, training, support and respite services for family caregivers. *Area Agencies on Aging*

## **FUNDING**

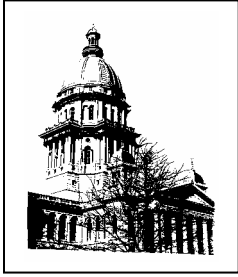
- Additional funding for long-term care can be provided through a Medicaid provider tax program, which brings in increased federal matching funds without any cost to the state general revenue funds. This would prevent a severe disruption to the continuum of the healthcare delivery system, help address some discrepancies in nursing home rates, and support other long-term changes. *Illinois Council on Long Term Care (ICLTC)*
- Implementation of such a tax should proceed carefully. Geriatric facilities currently pay a provider tax of \$1.50 per bed per day, and facilities for the developmentally disabled pay 6% of net revenue (the maximum allowed by federal law). The dollars raised through these tax programs receive federal matching funds. Last spring, there were some initial discussions about increasing the taxes. The financial condition of the profession is such that payment of additional taxes in advance of significant increases in reimbursement levels would be difficult. Facilities are juggling mortgage payments and food bills, and working closely with creditors to manage limited resources. All funds generated by a provider tax should be earmarked for long-term care and structured so that taxpayers receive maximum benefit from the additional revenue. *Illinois Health Care Association*

## **SENIOR CENTERS**

- Senior centers are the front line of preventative support services for the aging population. They can spot changes, crisis and isolation before any other long-term care provider in the continuum. They can intervene early with information and support services to lift that senior out of depression and out of isolation and crisis. Centers help seniors to maintain the lifestyles with dignity and respect. *Association of Illinois Senior Centers*

## **LONG-TERM CARE INSURANCE**

- Work diligently to increase the number of Illinois citizens covered by long-term care insurance to decrease the state's future liability. There have been attempts in the past to create some incentives for the purchase of long-term care insurance. But, frankly, the incentives proposed in past legislation have proven to be of little benefit. We need to get serious in our approach to these incentives so that the average citizen will be encouraged to explore the benefits of such coverage. The state, too, must do a better job of marketing long-term care insurance to its employees and their families. *Illinois Health Care Association*



---

# SPEAKER'S SUMMIT ON SENIOR SERVICES

---

## LONG-TERM CARE

### SUMMARY OF TESTIMONY AT STATE SUMMIT MEETING

OCTOBER 7, 2003

ROOM 114 — STATE CAPITOL BUILDING — SPRINGFIELD, ILLINOIS

#### **DONNA FOLKEMER**

NATIONAL CONFERENCE OF STATE LEGISLATURES

---

Medicaid is a primary funder for nursing home coverage in the country, 2/3 of nursing home patients on any given day. Across the country, about 70% of the Medicaid long-term care dollars are spent on institutions and 30% on home-based care. There are increases in costs of Medicaid long-term care services in both institutional and home care environments.

All of the states are facing budget crises. They're seeing a decline in revenues. As states face fiscal challenges, they are looking at areas in which there are extensive state expenditures, and Medicaid is one area getting attention

Most of the recent growth in Medicaid expenditures has been driven by increased enrollment, particularly children, and increased per capita costs in the areas of hospital services and prescription drugs. At the same time, the elderly and disabled population in Medicaid accounted for close to a 60% of the cost increase between 2000 and 2002, a lot of that being prescription drug expenses and hospital services.

One thing that we're noticing is that occupancy rates in nursing facilities are down across the country. Charlie Herrington has found the rates were about 90% in 1995 and have declined. The most recent figure is 83%. Most analysts are predicting a continued decrease in occupancy at least for the foreseeable future.

Another thing we're observing is that nursing facilities have evolved. The function of a nursing facility is changing rapidly. When you look at admissions to nursing facilities, there are more short-term admissions these days, post acute admissions and other short-term admissions. There's more focus on Alzheimer's disease and related disorders and issues — special units to deal with them.

The changes in occupancy seem to be related to medical advances. Services can be provided in more settings. There are more things for people to choose, and they're choosing them. A lot of it has to do with market forces — people choosing to have services in other settings, and some of those settings being more available.

We have also seen a doubling of residential assisted living options in the last decade. Patterns are not even from state to state, but essentially a doubling of residential and assisted living options. We see many more Medicaid home and community-based waivers for all populations. As of last year, 41 states use their Medicaid home and community-based waivers, which covers care in the home and some services in residential settings.

Medicaid home and community-based waivers started out as an exception, something that was different, but they are now mainstream. States are using Medicaid home and community-based waivers for all of their people that have disabilities and frail elderly persons.

Another important element is that there have been some changes in Federal policy recently that encourage consumer-direction in services. Most recently the federal government has put together some templates that allow states to do more in consumer-direction.

About 2/3 of the expenses for long-term care are for persons with developmental disabilities. The developmental disabilities field very early moved to the notion of building up services in the community, so more of the expenditures are for the developmentally disabled. Those individuals often have very extensive needs that increase the cost.

It doesn't seem that long-term care services have been disproportionately affected by the states' budget shortfalls, but many states' provider rates were frozen for a variety of providers, including long-term care. Many states put a freeze on waiver-slots that they intended to open. So there have been some impacts due to budget issues this year. It's going to be another tough budget season, as states get ready for 2005.

The upside is that we've seen the budget crisis spur increased interest in planning for the future, with most states restructuring service delivery and financing.

Legislatures everywhere and policy makers are discussing the Olmstead Supreme Court decision. That decision is not about Medicaid. It was about the Americans with Disabilities Act. It basically said that medically unjustifiable institutionalization is discrimination. What that means in practice is playing out in courts all across the country. Most people looking at this decision see it as something that will be affecting policy making for many years to come. It is something that is very significant.

States are strategically planning around long-term care. They're also trying to sort out where the Olmstead decision fits. The Olmstead decision used terms like "reasonable modification," and it said that courts can order states to make reasonable modifications in their public programs to move toward community integration. Courts cannot order states to make fundamental alterations in their services. Fundamental alterations are part of what legislatures do.

Some recent decisions center on another phrase in the decision, which is "reasonable pace." States need to move at a reasonable pace to assure community liberation for persons with disabilities. Some of the decisions are looking at the cumulative picture of a state's effort to achieve change, and when a state is making both reasonable modifications and fundamental alterations, which shows a pattern of a reasonable pace of change.

It's a complex decision. When we look at what states are doing, they're typically making reasonable modifications, and, over the long-term, looking at some fundamental alterations to improve their system.

The elements of the Olmstead decision fit very nicely with the kinds of things that we often think of when we talk about strategic planning, such as "community integration." What does that mean? What are the elements of this initiative? What kinds of supports and services are needed in order to make it happen? What benchmarks are needed to measure progress? What kinds of delivery models are out there? How do you measure individual outcomes? How do you document progress?

The Olmstead case establishes guideposts for strategic planning, including:

- promoting consumer choice of providers, settings and services;
- seeking maximum service benefit for the dollar spent, which typically then means looking at the sets of services that people want and need;
- reducing reliance on services that might be more restrictive than people want;
- promoting high quality and optimal outcomes; and
- making the system understandable, accountable and affordable in the future.

Consumer-directed care may involve individuals hiring their own workers. It may also involve a less dramatic change than that, by simply giving consumers more choices of services.

Managed care, prospectively paid long-term, is another model. Twenty states have at least one model that can be classified as managed long-term care, which is where financing and service delivery are integrated, typically with a capitated payment.

The Lewin Group recently identified some best practices in home and community-based waivers in three states: Colorado, Washington, and Wisconsin. Home and community-based waivers in those states seemed to be responsive to what consumers want, and seemed to provide a set of services that are consistent with what's needed in the state.

Lewin identified 4 common themes that enabled these states to reallocate Medicaid funds from institutions to home and community-based services. The states that did well with waivers had some kind of controls in place to manage home and community-based services' growth and its impact on service provision. The states that did best have strong locally-based systems with a single-point-of-entry, where issues around functional status and financial eligibility can be determined, along with other services like information and referral. They have streamlined provider enrollment activities, so that providers know where to go and where to sign up.

Colorado was one of the early states that had a single-entry-point. They have a system where they issue an RFP in particular regions and then identify an entity to be the single-entry-point. They have a variety of types of entities that are the single-entry-points. Some of them are county human services agencies. Some are Area Agencies on Aging. Some are nonprofit organizations. In rural areas, public health agencies serve that function. They have a fast-track eligibility function for people in hospitals so they can move them more quickly into the waiver situation, and so that they can get the community services more quickly. They have a *per capita* monthly payment for case management activities provided by the single points of entry.

In the state of Washington, another state that's been around awhile with a single-point-of-entry, they have state staff at local locations doing the level-of-care determinations and the financial



eligibility determinations. Most of the case management is being done by area agencies on aging. Over half of the people use independent providers for services. They have a strong role for independent providers — i.e., individual providers as opposed to agency providers. Like most states, they are struggling with limited resources. They have had to limit the number of hours that all individuals receive services. They've now developed a system of allocating more resources to individuals with higher levels of disability, and less to others.

Vermont has a strategic planning process. There's a website with information about that initiative. They have done several things. They've looked ten years ahead to try to determine disability patterns. They used a simulation-model put together by the Lewin Group. They've done a lot of work. They set a case mix goal for of home and community-based services and nursing home beds. They want 40 home and community-based services slots for every 60 nursing home beds. They have hard numbers on the need for services that guides planning, and specific targets for services that they want to have in place. Looking at some of the data, looking at where it's going to take you in the future, is a key element of what they have done.

Wisconsin is known for their current system and also their strategic planning process. They are the state that has probably moved the farthest with what we call managed long-term care. They have something called family care in several counties. They are providing a monthly payment that includes funding for nursing homes, community services, and administrative costs. It's all bundled into a single payment based on the average cost, as it is done in managed care and acute hospital settings. This is not something that you do overnight, but they are pleased with the results of integrating the payments, and then integrating the county resource centers, which are single-point-of-entry for everybody, offering advice and information. Individuals that qualify for services are overseen by county care management organizations. That system moves from information to care management and oversight. They have a website about that reform. They wouldn't tell you that they have this problem solved. There isn't any state that would tell you that, but I think trying to revamp their system to deal with some of the issues that continue to exist, including the fact that the family care system doesn't exist in every place in the state. They want to try to see if they can come closer to making it happen, including workforce issues and similar matters.

In Texas they passed a law that allows people who are in nursing homes who want to move into the community to jump the waiver line. It's a special allocation of dollars in the waiver program for people who want to leave institutions. The money essentially moves in the budgeting system from the nursing home line to the community services line for those people that leave the institution. It was modified somewhat this year. It's something in which Texas is very pleased. Some states are not thrilled with that idea, because it gives preference to people who are in institutions for services, but it is something that is getting a lot of attention.

**JAMES VARPNESS**

DIRECTOR, AGING & ADULT SERVICES DIVISION, MINNESOTA DEPARTMENT OF HUMAN SERVICES

---

*(See Attachment C for power point presentation that guided this testimony)*

Long-term care reform in Minnesota birthed out of the “2030” project in 1997 and 1998, in which town hall and main-street meetings all across the state were talking about the demographic shifts that were going to be occurring. This was called “2030,” because that was the date in Minnesota where the 85+ population more than doubles. That got people very nervous. It got to be very scary, specifically about state finances. The state legislature was looking at how

Minnesota needed to change, in terms of mainstream services, specifically in terms of the impact on the state budget, and particularly for long-term care. From that discussion, the Governor became very interested in long-term care reform and established a long-term care task force.

Those were the days that Minnesota was “tri-partisan.” The Governor was an Independent. The Senate was under Democratic control and Republicans were in the majority in the House. Each group had a number of people on the task force. There were also several commissioners from the Executive branch.

The task force used a process fairly similar to the discussion about demographic shifts in our “2030” project. It conducted hearings across the state, with task force members looking at a lot of the data, looking at budgets, and talking about what could be done to better balance the long-term care system, which, like many states across this country, was extremely biased toward institutional care — just the opposite of what people are mostly looking for and what we certainly heard from mainstream Minnesotans.

Minnesota is a strong, county-based system. Long-term care is administered through our long-term care human service agencies at the county level.

Minnesota's process was based on a planning process and on establishing benchmarks that we used to help us understand how well we were achieving a more balanced long-term care system.

Minnesota spends about \$1.1 billion annually for long-term care of the elderly, about 78% of our federal and state Medicaid budget. All the state aging program dollars are included in that amount. About \$890 million is invested or spent on nursing home care, and \$250 million, about 22%, is spent on home and community-based care. In 2000 and 1998, which really is the benchmark year, the amounts are similar. The home and community-based services were about 14% and our institutional care spending was 86%.

Some changes have occurred within past 2 years. There have been some shifts, moving into the home and community-based service side, which is what Minnesota is attempting to accomplish.

Minnesota has an elderly (Medicaid) waiver and a state-funded-like-waiver program called the Alternative Care Program, which serves about the same number covered by the elderly (Medicaid) waiver program. There is also about \$15 million spent through aging service grants that are really supplemental grants to the Older Americans Act aging network system.

The task force came up with a number of recommendations. Details are available on the state's website — [www.dhs.state.mn.us](http://www.dhs.state.mn.us). That site includes specifics, numbers, and percentages and also some of the planning documents.

The long-term care task force looked at what can be done to become less reliant on long-term care institutions, and what could be done to better provide for those individuals at the lower income and moderate income levels, in terms of more home and community-based service options.

One of the things that became apparent in the marketplace is, if a person had lots of cash, he or she had a lot more opportunities to look at other kinds of home and community-based service models. A “Gaps Analysis Process” found that, if the person lived in the right area, it really

didn't matter if he or she had a lot of money, or not. The services simply didn't exist on the home and community-based service side.

The task force established six broad policy directions for long-term care reform in Minnesota.

- Maximize the ability of people to meet their own long-term care needs. The largest purchasers of long-term care, or the decision-makers who determined where services were obtained, were individual consumers, their family members or spouses. Too many of these folks don't understand all of the different options. They see the bricks and mortars of the nursing home, and they believe that is "long-term care." In Minnesota that has essentially been the only option for years.

The task force really wanted to focus on giving consumers more power -- better information, more resources to make better choices and to understand the various kinds of options that were available in the community, and also to inform consumers about more ways of paying for long-term care privately -- i.e., long-term care insurance, home equity loans, etc.

There was an emphasis on "choice" -- trying to reform the system, so that there are more choices that were meeting people's needs and preferences, and looking at a more consumer-driven system, rather than the provider-driven system that was already in place.

- Simply expand the capacity and availability of community options in Minnesota. A little over half of the population -- about 5.5 million -- lives in the Metro-area. The rest, about 45 percent, is rural. It's largely a rural state. One of the problems in rural Minnesota is that there are very few options. In many areas of the state the only option for home and community-based services might be the services that were provided by the county for (Medicaid) waiver programs, aside from some home-delivered meal programs and services through the Older Americans Act and area agencies on aging. This was particularly disturbing to the task force, which then focused on expansion of home and community-based service models, and on the development of more options for consumers which more directly related to consumer needs and preferences.
- Reduce the reliance on the institutional model. The task force looked at the numbers in terms of the state and federal costs of institutional and home and community-based services. Nursing homes cost about \$48,000 a year. State costs on a monthly basis, subtracting an individual's share, are about \$3,200 a month. Home and community-based services paid under the (Medicaid) waiver, or the waiver-like-programs in 2003 are about \$850 a month.

The task force also looked at the demographics to try and determine how more individuals can be served in a more cost efficient way, and still meet the choices and preferences with the same kinds of dollars and mix.

- Achieve quality and good outcomes in our system. One of the real concerns of the task force was building a decent quality system and providing some basic measures for consumers to do comparisons between providers and try to identify quality measures.
- Support informal networks of family, friends and neighbors. In a 1995 survey of older Minnesotans, or individuals that were living at home, 95 percent of the long-term care supports were coming from family, friends and informal networks. The task force was very concerned that any expansion of the system not substitute government paid services for those being provided by family, friends and neighbors. That is a big challenge. Family

structures are changing significantly. Minnesota has one of the highest number of women in the workforce, and it has been well-known that for long-term care the best care insurance is having a daughter, or daughter-in-law. The task force was concerned about providing support and assistance to families, so that they stay involved and continue to do good things for members of their family.

- Recruit and retain a stable workforce. A particular challenge in long-term care, in both nursing home and home care, is the fairly low hourly wage rates and the affect that has in recruiting and retaining people into this workforce.

The task force met when the economy was much better in Minnesota, and when there were real staff shortages. A blessing about today's crappy economy is that the problem facing us today is not as serious.

Long-term care reform has to be budget neutral. Minnesota's long-term care reform package is built on the downsizing of the nursing home industry, and reinvesting those dollars in home and community-based services. That's essentially what the 2001 legislation does, and that's how the state identified and found funds to invest in a number of these proposals in the process of long-term care reform.

- The most important part is the expansion of the information and assistance system, and trying to move toward creating important single-entry-points for people into the long-term care service system, for governmental and non-profit, and for-profit services. The Minnesota legislature provided significant dollars in this area to create a comprehensive database of all long-term care and housing services in the state. This provides a comprehensive database online for use by all long-term care consultants, including the people that do the screening for nursing homes placement, or for home and community-based services. It is also a database for hospital discharge planners and other social service and public health nurses throughout the state. That system is now up and running. Information is being added to include most of the for-profit services.
- An additional piece of that system also relates to the actual assessment process, or the functional assessment and eligibility determination for home and community-based services. It also includes an income and asset eligibility test for the medical assistance waiver and state programs. In 2005 this system will be integrated into a more comprehensive system that will also include intake for the medical assistance waiver and State programs, all Minnesota healthcare programs, and also determine functional eligibility for waivers.
- There was also the design of the long-term care consultation system. Prior to 2001, Minnesota had a pre-admissions screening program that, for most people, became a *pro forma* process that reviewed certain particular functional requirements in determining if a person would either go into a facility, or qualify for home and community-based services. It also established the level of care and the rate of payments. The objective was to take that pre-admission screening process and change it to a long-term care consultation process, using social workers and health nurses at the county level. These consultants would provide assistance to people that were eligible for our programs, and also to other private individuals in helping them access particular services -- help them pull all things together.

In Minnesota, we have universal screening. Everyone has to be screened to go into a facility. If you meet the requirements for nursing facility care, you do have a choice: You can go into the nursing home, or you can take home and community-based services. So you aren't required to do one or the other. Generally speaking, that's not a problem. Most

folks are looking at other kinds of options, particularly when you're able to provide some residential options.

- There are also community-based service development funds. The legislature provided \$6 million a year to expand community-based services. One of the major areas and interests of the State was providing much more housing and service options, including affordable housing and assisted living services. We had very few assisted living opportunities for individuals that were participating in the waiver programs. More assisted living services offer the best substitute for nursing home care in terms of providing assistance for individuals with medication management problems and dementia problems. Money was provided for nursing homes for capital projects to re-configure wings to provide assisted living services, daycare services and other home and community-based services -- essentially trying to encourage the industry to get into the home and community-based marketplace.
- Minnesota also increased funding of the elderly waiver and alternative care programs. Significant dollars were reinvested into these particular programs based on projections and forecasts of the number of facilities that would voluntarily come forward to close beds. The state estimated that about 5,000 beds in Minnesota would close during the 2-year biennium, and the dollars saved would be used to finance assisted living and diversification projects.
- The task force developed an incentive for voluntary nursing home bed closures. There was a need to guard against beds leaving the market where there was a need in the system, and where there were projections based on the "2030" demographer that indicated a need for beds in the future. There was a need for careful investment in building the nursing home stock in the system. This is a voluntary system, which helped in getting it passed through the legislature. Facilities were not told: "You have to come forward." Incentives were provided to come forward. The incentive was \$2,080 for each closed bed. That amount would be moved into a home's base rate. So, some of the savings went back to the facilities, while other dollars were moved into investments in the long-term care system, including cost-of-living adjustments for both nursing homes and home and community-based service providers. That was really important, because we had been more generous with cost of living adjustments for nursing homes than for home and community-based services. The incentive program cost approximately \$8 million
- There were also proposals and initiatives to further strengthen the long-term care workforce. Dollars were provided to facilities interested in providing scholarships to their workers to advance in long-term care. The conditions required the workers to stay in long-term care for a set amount of time. The State provided participating facilities additional revenues on a per bed basis to develop scholarship programs to send nurse's aides to LPN, or RN training to help them advance careers and hopefully keep them in long-term care.
- Initiatives were also added to enhance quality and consumer satisfaction. The idea in this case is to establish report cards on nursing facilities and also on home and community-based service providers.
- What would a long-term care reform proposal have without somebody designing a long-term care payment system? This is a process that actually has been on hold. The goal is provide reimbursements based on quality of care. That is now on hold. It will be moving more toward a simplified reimbursement system, for which details are not currently available.

- The legislature provided funding to counties and area agencies for planning and development. This was critical. The counties and aging agencies will enable the state to take stock of what is being invested and what kind of services were being provided, so the state could have an accurate (road) map – showing which areas were rich in services and which were not. This will enable us to use funds to focus on areas in greatest need of development – where people have few choices and greater service needs.

What has happened with long-term care reform over the past couple of years? First, the state has come close to its mark. 4,000 beds have been taken out of the institutional system. That's really important. There are another one-thousand beds that facilities have applied to close. This has been an advantage for facilities that have low occupancy rates. It can be a very good deal for them by pulling those beds out of system and get a bump rates..

There has been an increase in the use of waivers. In 2000, 34% of the older persons served in the long-term care state and federal systems in Minnesota were served in home and community-based services. In 2003, 47% are served in the community. That has increased the average monthly cost for community care. This increase is primarily due to people requiring more intensive care in home and community-based care settings. This is also due to the provision of more affordable housing options, more assisted living options for individuals and more in-home personal care options. In 2000, the monthly average cost was about \$550. The monthly average cost in 2003 is \$850, again primarily because of higher assisted living costs.

The information assistance and access system is moving forward. The goal by the middle of 2005 is to have a fully integrated, single-entry-point for people to access all services, including a process by which a person can, either on-line or by telephone, as well as on a face-to-face basis, access the system and make application and become eligible for state programs.

The task force set some benchmarks for the state to judge how it was doing under the reforms. One benchmark is the ratio of nursing home beds per thousand elderly over the age of 65. Minnesota is quite a bit above the national average – about 54. The current rate is 64.6. It's going down gently, but it's going in the right direction.

Minnesota is serving more and more people and spending more for home and community-based care, about 22% in 2003 (estimated). That's more than in 2000, which was about 14.4%. The expectation in 2004 is around 27%.

With regard to supportive housing: In 1999, there were about 99 units per thousand people over 65, and now that is about 115.

In terms of case mix, performance is below expectation. Minnesota has a classification system "A" through "K". "A" is the lowest level of care in nursing facilities. There is still a fairly significant number in that classification; close to 15%. That number has not gone down an awful lot. Maybe it's the cold winters.

The percentage of non-case mix "A" elderly in waiver programs is very promising. These are cases involving heavier levels of care, and that's a really important piece. This demonstrates that these individuals can be served in home and community-based settings.

The nursing home industry in Minnesota has adopted what it calls its "long-term care imperative," under which it is also embracing the need to further balance the system by providing more home and community-based services.

Trying to get just workers and accounting systems, the care systems, and the hospital systems to start talking and focusing more on keeping people in their homes is really an important change in thinking. Helping to transform counties and also the voluntary and community resources are other measures of success.

Public financing will continue to be a major factor in long-term care. Private options are growing, but are never going to close the gap because of the high cost and the lack of insurance and other methods for protecting against the cost of long-term care. There is more shifting to community and consumer-directed care. The state needs to maintain its long-term care reform principles, measure progress and take opportunities that arise. There is also a need to promote more non-government financing and financing options. There may not be tremendous promise in that area, but there should be as many tools for people as possible to provide some protection and financing of their long-term care needs. Information systems need to be expanded to support of family caregivers, which is a real key and critical part of any long-term reform package.

**CHRISTINE GIANOPOULOS**

DIRECTOR, BUREAU OF ELDER & ADULT SERVICES, DEPARTMENT OF HUMAN SERVICES, MAINE

---

*(See Attachment D for power point presentation that guided this testimony.)*

Every state has to come up with a strategy or a solution that really best fits its mix of circumstances.

Maine started its long-term care reform efforts on January 1, 1994, so it is just about the 10<sup>th</sup> anniversary.

Illinois has a lot of the structure and the elements already in place to be moving its long-term care system forward.

Maine started this process to reduce reliance on nursing home care. In the 1980s and early 1990s Maine had greatly expanded its nursing home capacity. It was a fabulous economic development strategy in a rural state like Maine, and it was done in spades. So when it found itself in the early 1990s with its first budget crisis, in a situation where the state was extremely reliant on nursing facility care, and that spending was increasing geometrically, the first goal was to reduce reliance on this type of care.

There have been 20 years of task forces and study commissions, where older adults told us they wanted options. They wanted choices. At the same time, there was no money, nor the political will for reform.

In the early 1990s when the state budget was going into freefall, that crisis presented the opportunity to do something about long-term care.

Maine wanted to offer older adults more choices in residential and community-based services. There was also a significant issue of the very disparate, uneven allocation of home care resources. It really depended on where you lived, as to how much and what kind of services you received. In a small state like Maine, people were much more sensitive and aware of that disparity.

There was also a need to contain the rate of growth in long-term care spending. No one went into this thinking that the state would actually reduce spending. The goal was to slow the rate of growth.

In 1993, the state was facing a very serious budget deficit, and at the same time nursing home spending had gone up something like 50% over the previous three years. The legislature was just desperate to find ways to balance the budget, so this provided the opportunity for reform. A proposal to change was presented to reduce nursing home spending by essentially tightening medical admission criteria. This may not be the solution for Illinois, but for Maine it was the hook that would get reform going. That was the first policy initiative.

Maine was a case mix demonstration state, so there was very good data covering many years regarding who was in nursing homes. About 15% of people in nursing homes had no Activities of Daily Living (ADL) needs. They didn't really need to be in nursing homes. They were independent in their ADLs. Why were they there?

The legislature was informed there were many people in nursing homes who did not appear to be there for any good reason. They could be served less expensively in the community. The legislature would not ordinarily have been sympathetic to that argument, because it's a little scary. The financial situation was such that people had to make decisions that they probably would not have under different circumstances.

The legislature agreed to tighten medical admission criteria. They also established a requirement that any nursing home facility project had to be Medicaid cost neutral, which meant that any facility that wanted to add beds, or do renovations, had to prove to us that they could do it within the money they already had. This has created a very interesting market in the sale of Medicaid revenue streams. It's been a significant element of the state's ability to contain that component of the system.

In the early years, after this change was implemented, nursing homes continued to admit private pay individuals and did not inform them that Medicaid had raised the admission threshold. This resulted in the situation that people would go into the nursing home, spend down in three months, and be surprised to learn that Medicaid wouldn't pay for their care, because they didn't meet the eligibility criteria. The nursing home industry must have thought that this would create pressure on the legislature to roll back the reforms. It actually had the opposite effect. The legislature was so irritated, because they adopted mandatory pre-admission screening for everyone. It never would have been enacted, if they had simply been told that it was the right thing to do. Illinois has pre-admission screening.

Maine uses a single statewide organization to do pre-admission screening for nursing homes, and for all of the other publicly funded long-term care programs. It's one agency. This organization is not a provider of service. There is no conflict of interest in making placement decisions. It also does counseling.

If you want to do long-term care reform, you can't just focus on the nursing homes. It's not fair. If you don't focus on the whole system, you just shift your spending issues from one setting to another. Over the course of the last ten years Maine has systematically reviewed, revised, and restructured all of the publicly-funded home care systems to also achieve the same goals that were implemented for institutions.



There is also an automated pre-admission screening process. A nurse uses a laptop computer, goes into the person's home, does the assessments and makes the eligibility determination right then and there. That information is filed that day electronically with the department.

Again in 2002, 2003, and 2004, the state faced budget crises. Ten years into this process, we had to determine what has worked. The state has shifted spending away from the institutional side to the home and community-based care side. It has also doubled the number of people who are using home and community-based services. One way to do this is to just ratchet down the whole system, but in a state with a growing elderly population, that wasn't a strategy that would work. More people had to be provided services less expensively.

Medicaid nursing home census is down by 17%. Discharges from the nursing home to home have tripled, and length of stay is down by half. One of the reasons is that, in addition to pre-admission screening, the same assessor who looked at the person before he or she went into the nursing home also visits that person once they have been admitted, to determine whether there is a continuing need for that type of care. I don't know if that is done in Illinois? That was a very critical factor in the Maine's success, because it has kind of changed the culture and perception of nursing homes. They are no longer a place where you necessarily go to die. It's a place where you go to get better, so that you can go home and have another crack at staying at home a little bit longer.

Maine spends about 1% of the total long-term care budget on pre-admission screening and maintaining that system, and that's a pretty good investment.

With respect to pre-admission screening, a nurse assesses the person's strengths and needs, and then the system shows the program for which the person would be eligible based on that person's functional assessment. In Maine, if you're not eligible for nursing home, and you're expecting Medicaid to pay, you don't get admitted. Private pay people have the same assessment, and they may opt for a nursing home placement, even if we tell them that when their money runs out they might not meet the Medicaid criteria. In those cases, the nursing home is at risk, if they accept that person knowing that they probably won't be Medicaid eligible.

Over the last ten years, Maine has taken about 20% of nursing home beds off-line. This is not quite as high as Minnesota. This was accomplished by imposing stricter reimbursement penalties on facilities that had low occupancy. The lower the occupancy, the less of a percentage of fixed, or capital costs that would be paid. That created a very strong incentive for facilities to take beds off-line.

Maine used a financial disincentive. What we said to nursing homes was that, if occupancy dropped below a certain percentage, 90%, we reduced the percentage of the facility's debt service mortgage costs that we would pay. That created an incentive for facilities to convert those beds to other uses. Many converted those beds to residential or assisted living. We started with 10,000 beds, and today we have 7,500, keeping in mind that we're a state that's about a tenth of your population. The state population is 1.2 million, and we have about 220,000 elderly.

I have someone on staff who we call "let's make a deal." She works very closely with individual nursing home providers to help them assess what they might do with that excess capacity and to just get them through the process. You have to have the supports in place to bring people, along, and I think that's helped a lot. We've tried to be as creative and flexible as possible around this cost neutrality, so that if you have excess capacity, you can sell the revenue stream to another provider, and that's proved to be quite popular.

Maybe two-thirds of nursing homes converted to residential alternatives. For the facilities who have done that, they are doing much better than those who haven't. They can offer people alternatives as their needs change, whether it's community placements or nursing home care. Financially those homes are doing much better than the ones who said: "No way. We've always been a nursing facility. That's all we'll ever be." Those homes are struggling.

The rate of the long-term care cost increase also slowed. Maine's average increase in total long-term care spending has averaged about 2.5% over the last ten years, and that compares with the national average that is probably more like 8 percent. The state has shifted the care setting from nursing home to either other residential facilities or home care. It has reduced per capita spending.

How did this happen? The budget deficit was definitely a factor. That disaster had a silver lining. It was very difficult in the beginning. Legislators don't like making decisions that are going to upset constituents, whether they are nursing home owners or families who suddenly found out that mom couldn't go into the nursing home under Medicaid anymore, because the admission threshold had changed. If the money had been there, the legislature would have said: "Okay, this was a lovely little experiment, but let's go back to the way life was." The deficit in Maine continued for several more years. Even if people wanted to go back, the money wasn't there. That had the benefit of giving the state time to allow the reforms to work.

This doesn't happen overnight. Even in Oregon, the masters of this type of reform, it took five years before they saw significant change. It can be discouraging when there is chaos in the process of reform.

There was very strong support from some key legislators. There was strong support from the Governor. Like Minnesota, in the midst of this process Maine had an independent governor who had run and won essentially financing his own campaign. He didn't owe anything to anybody, and he could really come to this process much more unfettered. Other elected officials are (probably) unable to do that, but it clearly helped.

There was also strong support from older adults and disabled consumers, who probably knew better than state authorities that nothing comes without some hard work and pain. They were willing to put up with the bumps at the beginning.

Having a single agency do pre-admission assessments definitely has been an important element.

Restructuring home care programs is another. It was done in a way that allowed us to reduce overhead and administrative expenses in those programs by about 20%. Those savings were invested in home care programs and in direct services.

Having Medicaid as a payment source for residential alternatives to nursing homes was absolutely crucial. When the process started, the nursing home were the all-purpose solution for whatever problem was out there. The answer was: "Put that person in a nursing home." The data showed that a lot of people were in the nursing home essentially for shelter and supervision. They didn't (really) need any nursing care. They didn't need assistance with activities of daily living. They just couldn't live alone.

Having Medicaid pay for residential alternatives to nursing homes has been critical. You can't go into a nursing home and say to somebody; "Well, you're better now; you don't need to be here;" and then not be able to offer them (an alternative) place to go.

Personal care was provided as an optional program under the State Medicaid program. Medicaid directors around the country break out in a cold sweat, because that type of care can become another uncontrollable cost center. Maine covers personal care under its Medicaid State plan, and it's a very tightly controlled program. That type of care is available as a benefit, but is also managed very carefully to keep the costs under control.

Changes were also made to the Nurse Delegation Act that allowed services to be provided at home that ordinarily had to be delivered in a licensed facility.

Last, but certainly not least, was, at the state level, a very competent, very dedicated, very committed staff, who have been with this process since the beginning. That was a real benefit, because they brought a lot of experience.

There was not a lot of planning. In Vermont, a neighboring state in New England, they've been planning for the last 20 years. In Maine, it wasn't so much ready, aim, fire. It was more fire, fire, fire, and then go back and do mid-course corrections. It is more a matter of what works in your state. In Maine the concern was, if you spend too much time planning, you can sort of talk yourself out of doing some things and taking some risks. Maine just charged ahead.

Other things that helped us included the excellent data systems. Data has been crucial in working with the legislature. Legislators often find themselves torn between the department as the payer and the providers, and the legislators are sitting there saying: "Well, who do we believe?" The data has been very helpful in providing objective information about what has been done.

In Maine, one department manages the system: The Medicaid agency — the state agency on aging, the licensing folks -- are all in one department. They work very closely together, and that has certainly helped move things along. There is also no county government. .

Going to a system of acuity-based payment has also been critical. All of the programs have been re-structured to very closely tie eligibility, scope of service, and payment. No one agency is getting high reimbursement to care for low-acuity people. In all of the systems, those issues are very closely tied together, and they're very similar. The higher the acuity, the higher is the reimbursement. The lower the acuity, the lower is the reimbursement.

There is also a good partnership with the University. In many ways they serve as the honest broker, when the legislature is looking at these issues and attempting to make a decision.

Ten years into this, Maine still faces a lot of challenges.

The labor shortage in Maine has been a problem, as in Minnesota. It's not as bad now, even though the economy is not good, but Maine is a state that is losing young people at an alarming rate. There is little in-migration of any kind. so the state is facing a situation, particularly in rural areas, where the elderly population makes up 25 percent of the total population in some of those counties. There is basically no work force out there to take care of them.

Last fall the legislature re-adopted a nursing home (Medicaid) provider tax. There was one in the early '90s. When times were good the tax was eliminated. A year or so ago, when things started getting bad, the legislature passed (the new) provider tax. The proceeds from that tax have been used to help with the state budget deficit, and to pay for rate increases across the long-term care system. Everybody shared in the proceeds from that nursing home tax — the nursing homes, home care agencies, adult day service providers, and residential providers.

The nursing home industry in Maine deserves credit. They could have easily dug their heels in and said: "No way." It's a sign that people agreed that you just can't raise wages in one sector of this system and not expect it to create problems in others.

In order to contain system costs, there have been sacrifices in some of the flexibility that existed in the past. There are very tight service authorization guidelines — down to how many minutes a person gets if he or she needs a bath. This sounds a little obsessive/compulsive, but it is an important method for assuring some equity in how limited resources are allocated and used.

There is a challenge of rising expectations. In a sense, the better and more accomplished, the more the legislature expected to squeeze out additional savings. Most of the savings have been pretty much wrung out of the system.

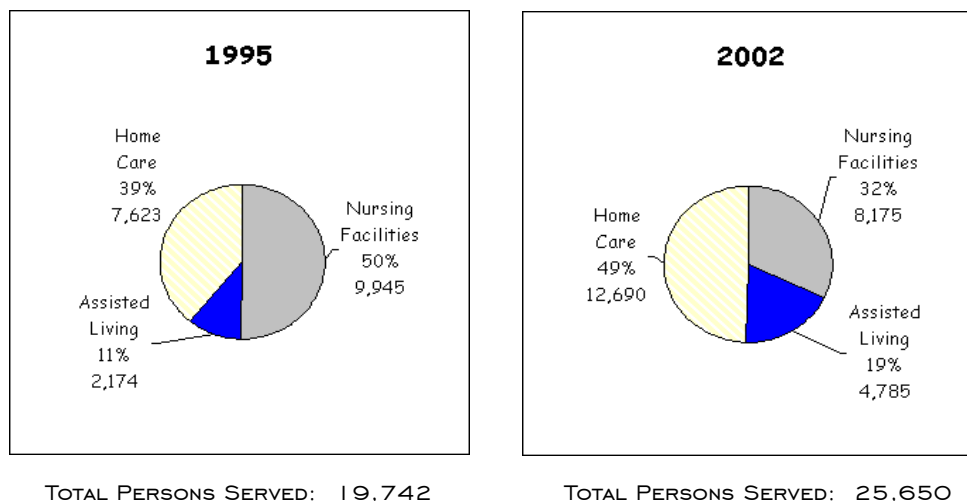
Another issue is managing high acuity consumers at home, people with behavior problems. These are individuals who, without a second thought, used to go into the nursing home. Now, there is an expectation and a system that says: "You don't go into the nursing home until you really need that level of care." So the people being served at home are not used to being called the nice little "blue rinse crowd," the nice little old lady who just wanted her knickknacks dusted. Services are being provided to very high acuity people, and that's a challenge to do that at home.

Because Maine is experiencing the same financial problems that many others are, it is, once again, facing a situation where State-funded home care programs have a significant waiting list, and it's hard to tell people that they have a choice when, in fact, one of their choices isn't available because there isn't sufficient funding.

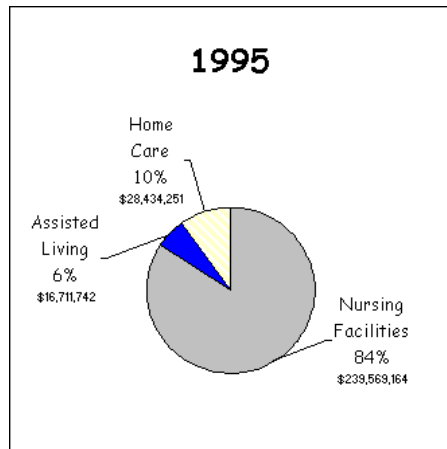
The charts below are basically what were used with legislators. It's just so simple. People understand it. They can look and say: "Okay, in 1995 this is where we were serving people, and in 2002, this is where people are getting services. It's something that most people can understand. It has been very effective in working with legislators to get them to see and continue to have confidence in the policy reforms. Maine is making progress.

## LONG-TERM CARE IN MAINE

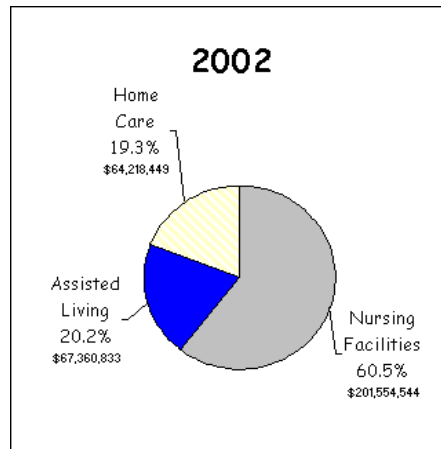
### WHERE ARE PEOPLE RECEIVING SERVICES?



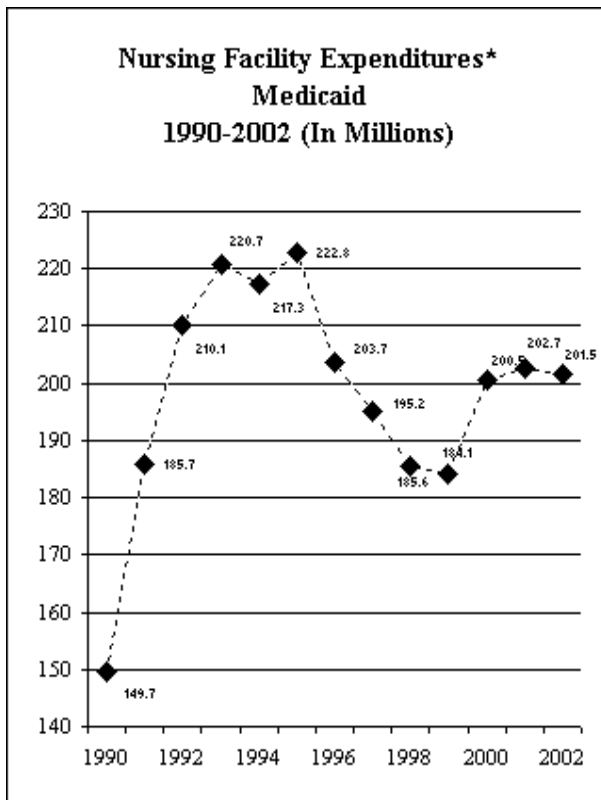
## STATE AND MEDICAID SPENDING



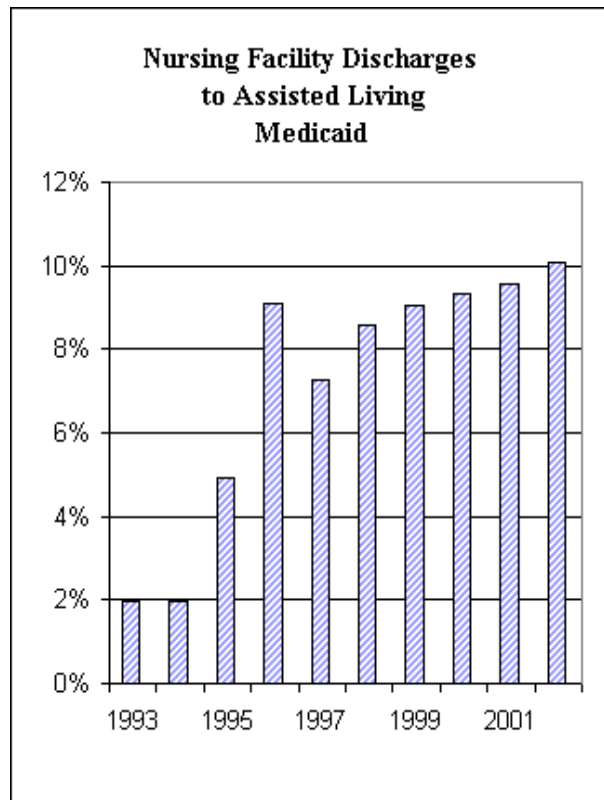
TOTAL EXPENDITURES: \$284,715,157



TOTAL EXPENDITURES: \$333,133,826

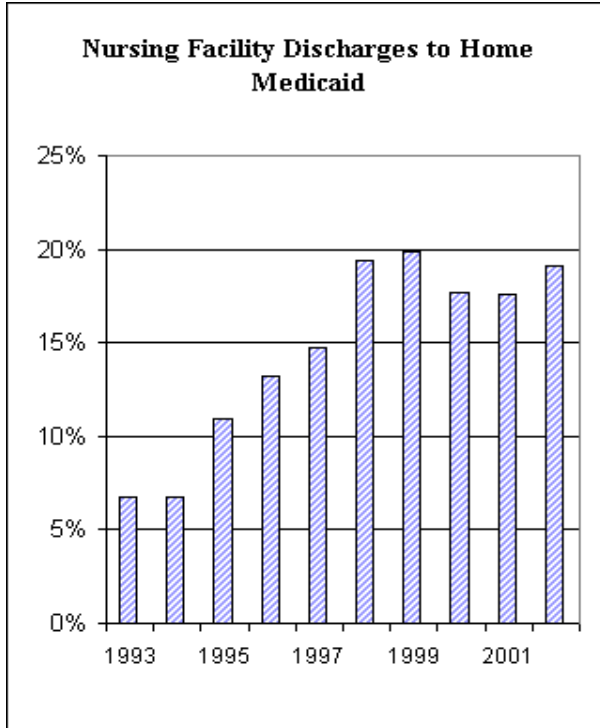


SOURCE:  
BUREAU OF MEDICAL SERVICES, 1/2/02

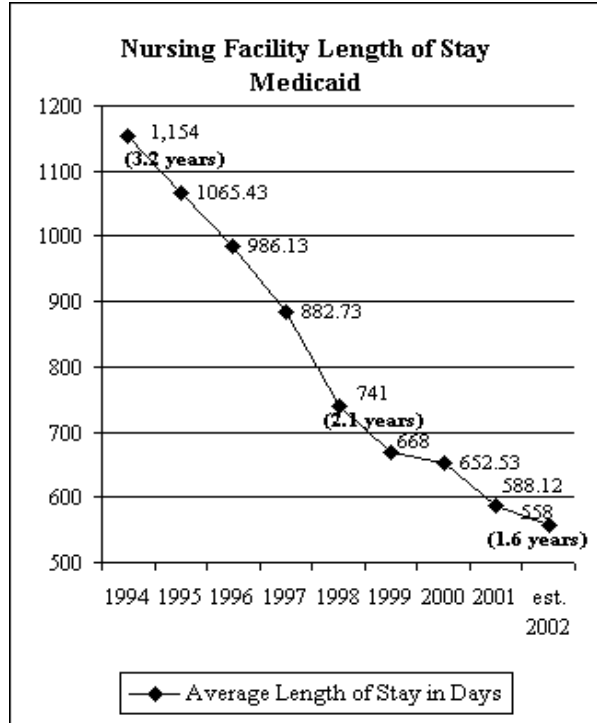


SOURCE:  
EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE, 9/12/02

\* ADJUSTED FOR GROSS RECEIPTS TAX, 1993-1998



SOURCE:  
EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE, 9/12/02



SOURCE:  
EDMUND S. MUSKIE SCHOOL OF PUBLIC SERVICE, 9/12/02

**LOUANNER PETERS**

DEPUTY CHIEF OF STAFF — SOCIAL SERVICES — OFFICE OF THE GOVERNOR

Generally, when we think of long-term care, we think of it being just for seniors. Of course there are many other categories. The state also has responsibility for any person who is disabled and needs extended care – i.e., those who have been injured and need long-term rehabilitation, or extended care, or children who may have a life-time disability. Those are all long-term care issues that have to be factored into the process, and they are connected in terms of the establishment and promulgation of policies, rules and regulations.

Just last week the Governor’s Office state health officials focused on the issue of nursing homes and physically fit, but mentally ill patients in nursing homes. There are approximately 16,000 persons with mental illnesses in nursing homes. About 5,700 are there just for the treatment of mental illnesses. The remaining persons require other kinds of medical services. Not all facilities are prepared to handle that population with multiple needs. We have situations in which people in nursing homes, who have worked all their lives as maids or laborers, and who did not have health benefits, now find themselves in a nursing home sharing space with other patients who are young (27 years of age), who weigh 250 pounds, who may be very aggressive, and who may be mentally ill or a substance abuser. Imagine an 80-year old senior who is located down the hall from such a person, and the senior is physically unable to defend him or herself?

Most of all, we want to make sure that we keep people at home, living independently, for as long as possible. All of us have parents who may be aging, and when we go to work every day, we want to make sure that they are well. Even if they're home, there is concern. Are they eating? Are they taking their meds? Are they letting someone in that shouldn't be there? Have they turned on the stove and the gas is leaking? Those are the kinds of issues that all of us have to deal with every day. They are critical. It may seem simple, but they are central to the question of helping people stay at home and staying independent as long as possible.

We also believe that home care will also reduce our medical costs, if someone is at home in their natural environment. We also think that it will reduce the cost of Medicaid, the cost of doctor's visits, the cost of medicine.

In most instances, if you are over 65, or over 70, and you go to a nursing home, there is an assumption that you're on your way out — this is the end. With that in mind, people tend to get sicker.

We need to work in partnership with the legislature. We also need to work in partnership with the long-term care industry, and with the citizenry. There needs to be a (better) balance of services. We have 79,000 people in the State of Illinois who are in nursing homes that are funded by Medicaid. That's a lot. We can't just say: "Well, we're no longer going to provide that service. We are going to divert, reallocate all of our resources to community-based care."

We have to figure out how to provide quality services for that population, and maintain those services, while at the same time creating enough options for the growing number of people who may not need nursing home care for a long period of time. We need that balance, so that we have options for people who want to stay at home as long as possible. It is a quality of life matter, as well as an issue of cost.

We must also have the infrastructure in place for those who may need nursing facilities. Not just in urban areas, but south and north of I-80. We need the same accessibility and the same quality of care.

Even in Maine there is difficulty finding staff to serve a growing elderly population. We have that situation in many places throughout the state.

The Governor has worked with legislators and expanded the senior care (prescription drug) program, with the goal of keeping people healthier longer.

In addition, we have increased the rate for the adult daycare services. We have to expand the availability of adult day care, because there are 60 counties without such services. That's a lot of counties that have no adult daycare services. Even with the increased rate, we've got to increase availability. I know the Department on Aging is trying to find additional resources in order to get more adult daycare services on-line.

We're looking for every opportunity to work in all areas of the state to try and get services, so people can stay home and live independently in their neighborhoods for as long as possible. At the same time, we have to provide quality care throughout the state for those who need nursing facilities. We have to address the issue of mentally ill in nursing home facilities. It is a critical issue. Much of it has to do with our regulatory issues. A lot of it has to do with budget.

## **MICHAEL GELDER**

DEPUTY DIRECTOR, ILLINOIS DEPARTMENT ON AGING

---

The Department on Aging is primarily responsible for distributing money from the federal government under the Older Americans Act. The department distributes this money to 13 area agencies on aging, which further distributes that money to local communities in support of about two dozen programs, from “Advanced Directives,” which helps people make end of life decisions, to volunteer programs, which help (dependent) healthy, very frail, and bed-bound elderly who choose to remain at home in their communities.

The department also manages the Community Care Program, which provides home-based care to residents who would (otherwise) be nursing home eligible. Illinois is somewhat of a model in terms of the breadth and scope of services it supports. There are about 39,000 seniors who receive care at any given time, probably 50,000 over the course of a year. These seniors are deemed to be nursing home eligible due to restrictions on their activities of daily living, and who need the services offered under a Medicaid waiver. The program is limited to homemaker and adult day services. There are a limited number of counties that have adult daycare services, but the recent increase in reimbursement rates over the last 18 months intends to stabilize the number of providers and attract additional providers into the program.

The Community Care Program also provides comprehensive case management services. There is a universal prescreening program, so that everybody about to enter a nursing home, or considering entering a nursing home, are seen by a case coordinators contracted through the department and local area agencies on aging. Case managers do the assessment, and if the person meets the need threshold, they are then given the choice of whether they want to remain in the community and receive adult daycare or homemaker services, or enter a nursing home.

The department may also be considered the eyes and ears of the senior community, through its information and advocacy functions. The agency administers an active senior help-line — an “800” number. Through hundreds of calls a day the department tries to guide seniors to appropriate service in the community.

The department also administers the Elder Abuse program. There are often cases where seniors are not protected and sometimes abused. They can be weak, alone, trusting and vulnerable. The program helps them, along with the ombudsman program, which represents seniors in nursing homes. Families and seniors can call to report potential abuses.

Seniors can't always advocate for themselves. The department can perform that function. Resources must be harnessed in a way that helps seniors meet needs in the most direct and cost effective way.

The department is committed to re-balancing the long-term care system. It's the number one priority. In the strategic planning process that the Governor has undertaken for all departments, there is agreement that the status quo is not tenable. The shifting demographics, the high level of dissatisfaction by the elderly in the community, in both institutional and non-institutional services, and the high costs being incurred, means more needs to be done — it needs to be done differently and better. The Department on Aging is committed to that goal.



## **RICK DEES**

ILLINOIS DEPARTMENT OF PUBLIC HEALTH

---

The Illinois Department of Public Health is the agency responsible for regulating long-term care facilities in Illinois. Currently, the department licenses approximately 1,000 nursing homes across the state, as well as 300 intermediate care facilities for the developmentally disabled.

The department regulates facilities in two ways. Under the Illinois Nursing Home Care Act, the home must have a license to operate. It must meet licensure standards, which are very comprehensive, addressing virtually every aspect of operation within a facility.

In addition to state licensure, any facility that participates in the Medicare and Medicaid program must also meet federal regulations promulgated under the Social Security Act. The department acts as the agent of the federal government in conducting the federal certification surveys, to assure that facilities that are certified remain in compliance with the federal regulations.

Approximately 90% of all the long-term care facilities in Illinois participate in Medicare and/or Medicaid, so the majority of the survey activities carry out two roles. The department conducts State licensure and Federal certification at the same time. The department conducts routine inspections of all licensed and certified facilities to ensure that they are remaining in compliance with the applicable regulations. At a minimum, the department conducts a full survey annually. If deficiencies are cited, the department conducts revisit surveys to assure that those deficiencies have been corrected. In addition, the department conducts complaint investigations when allegations of noncompliance are received by the department.

The survey process is highly prescriptive and complex. On average, it takes a survey team of five individuals approximately four-to-five days to complete a full survey at a nursing home. The survey teams for the department consist primarily of registered nurses, but also include licensed environmental health practitioners, licensed dietitians and licensed architects.

In 2002, the department conducted 14,150 different survey activities in regulated long-term state facilities. This included approximately 5,500 complaint investigations. In 2002, approximately 78% of all of the facilities surveyed had at least one substantial deficiency. On average during 2002, the department cited six deficiencies during each annual survey. The majority of the facilities that the department surveys correct their deficiencies at the time of re-inspections.

There is a significant enforcement aspect of our program. There are fines and penalties that can be applied to problem facilities under both state and federal regulations. A recent U.S. General Accounting Office report on enforcement in nursing homes included state-by-state statistics regarding the application of federal fines. That report indicated that between January 2000 and March 2002, the Department of Public Health's long-term care survey program assessed \$2.8 million in federal fines against long-term care facilities in Illinois.

The ultimate penalty within our licensure program is the revocation of a facility's license to operate. That is a last resort. It is only pursued when the department finds a pattern of serious problems that the facility is either unable or unwilling to correct. When the department pursues revocation, it needs to keep in mind that the first individuals impacted by facility closure are the residents of the facility. So when the department proceeds with revocation, a determination has been made that the health and safety problems that have been identified outweigh the negative impact of moving those residents out of that home.

The ultimate penalty under the federal certification program is decertification – i.e., the cutoff of all Federal funding to that facility. The threshold for decertification is much greater than revocation, so a facility can be decertified, but continue to have a license to operate. Most often decertification makes it financially impossible for a facility to continue operation.

The department operates a nursing home web page where the public can access information about all long-term care facilities regulated by the department. The page includes information about every regulated facility, and includes a guide on how to choose a nursing home. It also provides specific data on each facility, including the ownership of the facility, staffing levels, information related to the types of care provided, whether they're Medicare/Medicaid certified, and what their private pay rates are. The page also includes actual surveys conducted by the department, so individuals seeking to place someone in the nursing home can actually review the deficiencies cited at that facility.

The department also operates a toll-free, 24-hour hotline for filing complaints. All complaint allegations are investigated by our surveyors. Depending upon the severity, investigations may be initiated within 24 hours if the allegation relates to some imminent hazard to a resident. If there's an allegation of abuse or neglect, the department initiates the complaint investigation within seven days, and all other complaint investigations are initiated within 30 days of receipt.

The department has a long-standing focus aimed at reducing the occurrence of abuse in Illinois nursing homes. The department has a working relationship with the Illinois State Police Medicaid Fraud Control unit, and it works with the department to address the criminal aspects of these investigations. Any allegation of abuse and neglect that the department receives is immediately referred to the Illinois State Police for them to determine whether or not there should be a criminal aspect to the investigation. The department plans to continue this role, and also to expand interactions with local law enforcement agencies, local prosecutors, and more recently, interaction with local coroners. The goal is to bring the full force of law to bear against those individuals who choose to abuse.

The issue of the relatively young, able-bodied seriously mentally ill in long-term care facilities is a priority for the department. Working with the Department of Public Aid, the Department of Human Services, the Department on Aging, and representatives of the industry and advocacy groups, the department developed a comprehensive set of licensure standards that specifically address the provision of mental health care to residents in long-term care facilities. The department is currently in the process of implementing those regulations.

In addition, in partnership with those other state agencies, the department is looking at the pre-admission screening process for the admission of individuals with serious mental illness into long-term care facilities. The goal is to assure that those who clearly need the services of a nursing home are admitted to a facility, and that the facility receiving them is able to meet their mental health needs.

During the course of these summits, the department has heard comments that relate to the survey process and the punitive nature of that process. The survey process is actually driven by federal survey protocols and, admittedly, the federal survey process is a somewhat punitive process. It relies solely on the application of fines and other penalties as the only means to assure compliance. Having a big hammer is very helpful in situations where you have serious problems that need immediate action. At the same time, having the hammer as the only tool available to you may not be an effective process. There may be regulatory situations where something other than hitting the facility with a hammer may be the most effective means of assuring facility compliance. With this in mind, Dr. Eric Whitaker, our director, is pursuing a

dialog with the federal government to discuss the possibility of some flexibility in the federal survey process.

One issue the department is looking at is the lifting of restrictions that currently exist on our surveyors providing direct consultation to facilities with problems – i.e., when the department identifies a facility with quality of care problems, it is somewhat restricted in consulting with that facility, or basically telling them how they can correct the problem and improve the quality of care.

At the same time, the director of the Department of Public Health will raise some issues related to increased flexibility in the application of the survey process. Illinois, as the case in many other states for a number of years, has raised concern about the prescriptive nature of the survey process and our inability to focus our resources within the confines of the federal survey protocols. The department is looking for the ability to use the federal survey process in a way that allows us to spend less time at good facilities and a great deal more time at problem facilities, where our resources are absolutely necessary.

## **ANNE MARIE MURPHY**

ILLINOIS DEPARTMENT OF PUBLIC AID

---

The Department of Public Aid funds several programs through Medicaid designed to meet the long-term care needs of Illinoisans. The department tries to provide a wide mix to meet all needs. The department attempts to encourage the appropriate delivery of quality services for the elderly, or those with disabilities who require long-term care in all settings, including home and community-based settings. There has been a good move in the last few years to provide more services in home and community-based settings.

There are a certain number of people who need a higher level of care that is provided in a nursing home setting. The department covers about 56,000 people in this setting in an average month. Nursing facility care is more expensive, which costs the Department of Public Aid about \$1.9 billion annually. Twenty percent (20%) of the Medicaid budget is spent on about 3% of the population. The 1.9 billion covers both the nursing home per diem and also ancillary services.

Medicaid is the largest payer of nursing home care in Illinois, funding about 65% of all nursing home residents. Illinois Medicaid actually funds about 92% of statewide costs. The program pays for ancillary services separately. Facilities are paid a per diem. Prescription drugs and other services are paid as an add-on. Many states wrap ancillary services into their base payment. For FY 02, Illinois Medicaid spent \$1.53 billion in nursing home per diem, and paid another \$441 million in ancillary services, including \$238 million for prescription drugs in the nursing home setting.

Illinois stood alone this year, during fiscal hard times, as the only state in the nation that implemented a large expansion of Medicaid coverage. There was an expansion of Family Care and KidCare. There were no cuts in provider rates, nor cuts in other benefits to beneficiaries. There was no curtailment of other eligibility categories. Many states had to cut services, some as much as 15% in the Midwest Region. They also scaled back benefits. Some also eliminated coverage categories. In many states, children lost coverage, disabled individuals lost coverage, and in some instances seniors lost coverage. Governor Blagojevich demonstrated a strong commitment to healthcare when the budget was pretty strapped.

The Illinois Medicaid program, in partnership with other agencies (the Departments of Human Services and Aging) has a variety of home and community-based programs. Over 51,000 seniors and persons with disabilities are served in these alternative settings. That's 51,000 Medicaid individuals. Several of the programs, such as the Community Care Program, also provide services for non-Medicaid individuals. That translates to about half-and-half, considering the 56,000 people being in nursing homes and 51,000 individuals being in community settings.

The department has in the last few years instituted an innovative program known as the Supportive Living Program — a form of assisted living. It helps seniors have one more option. There are currently 29 supportive living facilities in operation, and another 41 sites under development. This type of care promotes personal choice, dignity, privacy and individuality for residents who use that service.

Illinois took advantage a few years ago of a waiver that the Federal government allowed for implementation of the Senior Care (Rx) Program, which allows us to provide comprehensive drug coverage to Illinois seniors up to 200% of poverty. The Governor would like expand eligibility to people with incomes up to 250% of the federal poverty level. Illinois has applied for this expansion with the Federal government, but it has not yet been approved.

The Senior Care (Rx) Program is a very comprehensive drug benefit. Compared to prescription drug proposals under consideration at the federal level for Medicare, it is a much more generous program. There is no enrollment fee. There is no deductible. There is \$1 co-pay for generic drugs and \$4 for brand names, up to a level of spending of \$1,750. After that threshold is reached there is 20% co-pay. It is a very generous program.

## **MARTA SAYEED**

ILLINOIS DEPARTMENT OF HUMAN SERVICES

---

The Home Services Program is housed in the Office of Rehabilitation Services within the Department of Human Services. The program is required to serve people who have disabilities between the ages of birth to 59, to help prevent institutionalization and, in many instances, come out of a nursing home. The goal is to provide community services. This is a Medicaid waiver program.

The Home Services Program began in 1979 as a very small program at the Department of Public Aid. It was transferred to the then Department of Rehabilitation Services. It was a very small program. We served 1,200 people. In the early 1980s, the Medicaid waiver was obtained, and the caseload has grown to 27,000 by the end of this year.

Since the program's inception, it has been based on the concept of customer choice. The majority receive home services, but given by personal care attendants. Those attendants are chosen by the customer, which means they are hired, trained, directed, and, if it doesn't work out, fired by the individual customer. It puts control of the services with the recipient.

One of the advantages of being in the Department of Human Services, together with the rest of a number of disability services, is that customers also have direct access to other services, including the vocational rehabilitation program that relates to some of the same customers. This

enables the person to more easily access other services in their home. The person might have other potential, including employment. The department may be able to address all the needs of the person.

The program has also developed good relationships with the disability community. This helps to guide the agency in doing the right thing and developing a program that is responsive to the needs of persons with disabilities.

The department also recognizes SEIU-Local 880, representing personal care attendants that work for our customers. An Executive Order was passed this year, and companion legislation, that has made them the sole representatives of our personal care attendants, and that has allowed us to sit down at the table and start serious negotiations. Everyone is at the table.

## **MARTHA HOLSTEIN**

HEALTH AND MEDICINE POLICY RESEARCH GROUP

---

A focus on long-term care has been important throughout our history because of its importance to local communities and ultimately to all of us as citizens and taxpayers. There is particular concern about developing new and better ways to keep people living in the community for as long as possible. Nursing homes are essential, but many people currently there can thrive in the community with adequate support.

The way any society delivers long-term care is important for many reasons: It signals the value of the oldest and frailest members. Major tax dollars are needed to pay for care for the growing number of the elderly and disabled populations. Many older people need care no matter how well they have cared for themselves over their life times. Physical and mental changes are common features of old age, especially advanced old age. When faced with these losses, the moral importance of home escalates. The desire to stay home is as important as the deep resistance that older people have about going to nursing homes. Home means something to everyone, and that meaning becomes even more significant as a person's life in the world narrows because of disabilities. Inappropriate nursing home placement is a contributing factor to morbidity and mortality of elderly.

- Financing is an unavoidable issue. Reallocation of resources from nursing homes to the community is a beginning, but other means to finance LTC must be explored with the retirement of the baby boom generation just around the corner.
  - ≡ Individuals are deeply concerned about their ability to finance their own long-term care needs and those of their older family members. This fear is particularly strong in the working middle class who have saved, but not enough to cover the costs of any extended need for care. The entire middle class feels disenfranchised.
  - ≡ State Medicaid recovery policies create considerable conflicts of interest for elders, families and providers. The idea of a financial legacy is very important to people. State recovery under Medicaid after death is like the estate tax for the wealthy. Repeal of the estate tax is designed to let individuals pass something on to heirs. That may not be possible for people who have some resources, but are on Medicaid. This is an area that needs to be re-examined.

- Families have not abandoned their elders. They provide 80% of all care, but life circumstances often make it difficult. They often experience guilt, burn-out and suffer economically and emotionally as a result of the caregiving role. They are usually women.
  - ≡ A more flexible system of services is necessary, so that care is focused on the person and his or her family.
  - ≡ Consider paying family members for the assistance they provide.
- Build upon Illinois's focus on client-centered care, so that the client becomes the center of a system that unites finances, services, and family.
  - ≡ Have funding follow the client, rather than cover discrete services. Other states, such as Wisconsin, are experimenting with county-wide programs that make access and eligibility determination simpler, while "bundling" resources to bring the client what he or she needs on an individualized basis. The state needs to be more flexible, to give the case manager more options and more latitude. Consider a "supermarket" system that allows flexibility in available services. Public money should be available to the eligible senior, regardless of the setting in which the care is provided. There should not be a bonus for getting care in a nursing home.
  - ≡ Assume that nursing homes are the alternatives to other ways of providing the help that older people need to live out their years with a sense of fulfillment and continuity with their past. Although we think of home and community-based care as the alternatives to nursing home, we should reverse that order. If there is any bias, it should encourage prolonged stays at home, in the community.
- Alter the way information about services are made available. Agencies that do case management and provide home care services operate on a normal business day. Nights and weekends and the lack of comprehensive information from any one source can become very difficult for the older person and his or her family.
- The federal Olmstead Act gives a particular impetus to the "choice" of keeping people in the community. Care at home and in the community-is important because, home is the reservoir of memories; it represents security; it is a piece of yourself and the source of pride; it is where we feel the most like ourselves because it is familiar; it is where the possibilities for real autonomy exists—when we can live in habitual ways; it is where the possibilities for real dignity exist—where people can be treated as unique individuals. If paid care can be well-blended, with care provided by families and friends ; it costs less than institutional care; and an older person has some control over the care that they receive
  - ≡ One's own home is not the only possible site of care in the community. It is important to consider how we might broaden the range of options for housing people in the community beyond home. In addition to assisted living and supportive living, we need to include such options as adult family homes and shared housing. Any housing would result from planning that included older people and their families and would be designed to facilitate privacy, support individual uniqueness, incorporate families and friends as partners in care in ways that are convenient and doable for them.
  - ≡ Develop programs that assist people in nursing homes to return to the community. Such a system would be good for the elder and would also provide the funds to significantly augment home and community based service wages and options.

- Take care of the caregiver. For care provided in the home and in the community to be of the highest quality, the individuals who provide that care—mostly women—must be paid adequate wages, be treated respectfully, and have built into their jobs the possibilities for advancement. The caregiver cannot give good care unless she is well cared for. Better trained and better paid workers are better workers. Adequate wages are more than just an economic issue for workers. It affects the way care is delivered and perceived by those who benefit from it.

## **DONNA GINTHER**

AARP

---

Maine obviously is a very small state, and it may not work here, but there are some lessons to be learned from that state. While Minnesota is much larger state, and looks a little more like Illinois, it has a county-based service delivery system, whereas Illinois has a completely privatized service delivery system that is dependant upon community-based organizations to provide services for most of seniors at the community level.

Illinois should enact a Senior Bill of Rights that ensures that a basic set of services, home, community and facility-based, is available to seniors throughout Illinois, regardless of the geographic area in which they live; that services are of the highest quality, both client- focused and consumer-directed; that the health, safety and well-being of seniors is one of the state's highest priorities; and that services available in Illinois promote the continued independence of seniors, as well as their autonomy, their dignity and privacy.

All providers — facility-based, home-based and community-based — and advocates should be at the same table to work through these issues.

The AARP has 2 overarching recommendations:

- Implement an incremental overhaul of the senior service delivery system, and realign the system to better reflect the needs and desires of all generations of seniors, including the newly-retired, the active-older-senior and the frail elderly; and
- The very basis of this overhaul is the need to expand home and community-based services statewide. There needs to be a consistent package of services no matter where you live.

Retro-fitting the existing nursing home, sheltered-care, facility-based system is inherent and critical. AARP began discussions with two of the industry groups, and this summer began discussions with the third about what that would look like. Nursing homes groups have been open and honest and have come forward knowing they have to change.

- Clearly one of the key pieces is taking beds off-line. One of the interesting things that Maine did is that they quantified the value of those beds that were coming off-line, and by law allocated the savings to the expansion of home and community-based services, which gave them a natural revenue stream. The Maine website, by law, charts where that money went every year.

- There should be a realignment and consolidation of administration of existing programs to better serve the elderly and reduce the state's administrative costs. There needs to be a single point-of-entry. There is money right now at the federal level to pilot for such an initiative. We need to do it now. It needs to be consistent from community to community.

The conflict of interest between the “gatekeepers” (those doing client assessments) and providers will have to be addressed.

Currently there is a searchable database in the Department of Public Health and a separate one in the Department on Aging. There should be one database that has home and community-based as well as facility-based care. A client should be able to go in and punch in in Macon County and see the kinds of services available in that area, and the eligibility standards and information about the individual providers. There should also be information about treatment centers for Alzheimer's, and about other diseases affecting the aged. Family caregivers should be able to access that information. They should also find information about providing care – i.e., how to feed someone who is lying prone.

- The health, safety and well-being of the seniors must be one of the state's highest priorities. There should be appropriate monitoring, not just of facility-based programs, but of home and community-based programs.
- There should be a single point-of-entry for complaints that uses the same standard definition to classify the cases, regardless of whether the person lives in a facility, doesn't live in a facility, has a family relationship with the perpetrator or not.
- Services must be of the highest quality, both client-focused and consumer-directed. Look at the existing consumer-directed pilot program and see if it's appropriate for in-home programs, to allow some seniors the flexibility of directing their own care. There must be appropriate safeguards to ensure that the individual is not going to be exploited, abused, and that fraud is not going to be perpetuated.

All providers, facility-based, community or home-based, need to be required to have quality assurance programs. They need to make routine reports to the state of Illinois. Every provider needs to have annual satisfaction survey, and the results should be available to the public upon request.

High worker turnover is contrary to the concept of quality. Illinois needs to develop career ladders with incentives for advancement.

*“One of my volunteers' daughters has been an in-home care worker all her adult life, and she's now in her late 30s, early 40s. She is going to be one of those people who is going to be poor as a senior, because she doesn't have a pension, she doesn't have health insurance. Why doesn't she move on? She's an intelligent woman. The reason is — she loves what she does. She loves every one of those seniors she takes care of. We should be promoting that, not putting barriers to people being able to stay and to grow within those fields.”*

- A basic set of services, home, community and facility-based, should be available to a senior, regardless of where they live in this state. Services are provided in a patchwork across the state.



- Services available in Illinois should promote the continued independence of seniors as well as their autonomy, dignity and privacy. Facility-based programs need not convert to assisted living, although certainly that is one way of bringing the beds off-line and meeting the demand. Facilities can implement client-focused models, including the Wellspring model, or Pioneer movement, or the Edens project. There are advantages and disadvantages in each of those programs. For example, a Pekin nursing home is now running a restaurant, a menu-based restaurant system for their meals, and it is open to the public. It is fantastic. The food is delicious. The residents are happy.
- There are 3 generations of seniors developing in this state. They are all going to have different kinds of needs and desires. The frailest and oldest in this state came out of the Great Depression. They remember the good old days of Model Ts and gas lanterns. The youngest generation come out of the 50s, grew up on the Beatles and think the Mustang was the coolest thing in town. These two generations don't always have a lot in common.

*“A few weeks ago I was in Oregon, and I was on a shuttle bus. I realized there was a senior center tour with me. I became interested when I heard a couple speak to another couple looking relatively my age, asking what time the senior center bus was going to go home, so I began to listen.*

*They had been on an excursion the weekend before to go body surfing and have a clambake on the coast, and in a few weeks they were all going to see the Simon & Garfunkel reunion concert. Now, the 90-year-old woman who was in that group and the couple that were in their 70s or 80s might not have been interested in that any more than the younger couple was interested in some of the things that the older people wanted to do. But the reality is, they had all come together to go to a salmon bake on the ocean.”*

## **MICHAEL O'DONNELL**

ILLINOIS ASSOCIATION OF AREA AGENCIES ON AGING

---

Ed is an 88-year-old gentleman currently residing in McClain County Nursing Home. He entered the hospital about three months ago, after falling in his double-wide home in Bloomington. The comprehensive and coordinated system in place, through the Area Agency on Aging, got to know him. He had already been receiving home-delivered meals for some time. His wife is in the McClean County Nursing Home and has been there for seven years with Alzheimer's disease. Twice-a-week a special bus from Bloomington-Normal Public Transit would pick him up and bring him to the nursing home so he could visit his wife. He had an established relationship with the nursing facility. When he needed care and emerged from the hospital, he asked to be sent to the McClean County Nursing Home, where he currently resides.

Earlier today we heard about the prospects of going home for nursing home residents, and his prospects are very good. He has been diagnosed as an insulin-dependent diabetic. He entered the facility already blind, due to macular degeneration. So the problem was: how does he monitor his blood sugar at home as a blind person; and how does he measure the doses and get the doses administered in a safe and proper manner? Well, they've got his blood sugar stabilized now, so he could store 30 units of insulin in his refrigerator at home, if he had someone to help him once a day administer that medication, and that's where the Center For Independent Living comes in. They have a blind outreach specialist who has been visiting him

for some time, helping him get assistive technology. So he's got all the bells and whistles at home, and able to live independently at home once he gets there, and they're helping him find a volunteer who is qualified to give injections once a day. His prospects for returning home within the month are excellent. This is a good example of a comprehensive and coordinated system of services, and that's the mission of an area agency on aging. It's bringing all the pieces together, both public and private, to make the system work for one individual.

We can do a much better job in making those kinds of connections uniform and consistent statewide. We should expect as much from the system in Bloomington as we do in Chicago or any other community in our state, but the playing field is not yet even, and we have to do that.

In the interest of improving the system, the Area Agencies on Aging make 5 recommendations:

- Expand eligibility for our home and community-based services, so that more senior adults can use them. This can be achieved by raising, for example, the asset limit to at least \$20,000 incrementally over a series of years.
- Expand the range of services available to help seniors live independently, and make those choices real, especially in an environment where people are staying at home with higher and higher acuity levels, by providing State funds for home-delivered meals, transportation and personal emergency response systems under our current Medicaid waiver. Improve access to health care and therapeutic services to help older adults manage chronic illnesses and disabilities more effectively. This was promised in 2000, but never realized because the funds were not appropriated. If the funds had been available, we could command Medicaid reimbursement for those meals, for those trips, and for those devices that enable people to live at home safely. This should also include empowering and training case managers, so that they can access more complex medical services for the clients who need the help.
- Build the capacity of our community-based providers to serve older persons. Increase state grant assistance to the Area Agencies on Aging for community-based services, not just for the information assistance and the home-delivered meals that you're familiar with, but for emergent needs such as medication management. There should be a nurse, or someone qualified, measuring out doses over a weekly or monthly basis, and helping those clients at home manage their medications. Increase reimbursement rates for services under the Community Care Program, to provide adequate wages and healthcare coverage to workers in the field of aging. Develop career ladders and provide continuing education to enable workers to advance in the healthcare professions, so that a homemaker who sees the need to administer medications, or drops, or injections for her client, has the necessary skills and supervision to provide that help.
- Build the capacity of our Illinois families to provide care, such as the Family Caregiver Act, which passed the House and is now in the Senate -- Senate bill 1620. Provide State funding for education, training, support and respite services for family caregivers.
- Improve community-based access to home and community-based long term care services through the Department on Aging, Area Agencies on Aging, their regional service networks, and culturally competent organizations. Include information on quality and affordability of long term care facilities, housing, and home and community-based services. Provide information on pre-admission alternatives. Utilize the most recent technology for service inventories, benefits eligibility, telephone transfers, and internet availability. Increase visibility and system access, and connections between all long term care service providers.

## **JULIE SAMPSON**

CITIZEN ACTION

---

The Long-Term Care Council legislation was signed by the Governor. The council will be composed of members representing all interested parties in long-term care: It will address the intent of the Older Americans Act with respect to the state Long-Term Care Ombudsman Program. The state ombudsman has a unique perspective, and there are important discussions in terms of system-wide reform that haven't taken place around that office.

The ombudsman program has proven to be both cost effective and a successful way to address all kinds of complaints and issues that come up for residents. The council will be effective at assisting families with everything, from understanding their rights to helping mobilize them through family councils, and working with facilities in terms of resolving problems before they get to an advanced stage.

## **MATT KEPPLER**

ILLINOIS ALZHEIMER'S ASSOCIATION

---

The Alzheimer's Association presented testimony at the regional summits across the state during the last three months. Additional recommendations include:

- Expand and promote home and community-based options. Public funding for long-term care programs is biased in favor of institutional settings, yet 70% of people with Alzheimer's disease live at home. Family and friends provide 75% of all care at no expense to the State. While this is the preferred option for many, not all Illinoisans can access the services they need, due to limits on program capacity, geographic barriers and income restrictions.

≡ Increase funding for Adult Day Services reimbursement and transportation line items.

The association is concerned about adult daycare, because it provides a structured program for people with Alzheimer's disease and related dementia in a secure out-of-home setting. Adult daycare is much more than respite. It's an effective treatment for people with Alzheimer's. Good programs that are tailored to meet the needs of the individual with dementia can reduce agitation, mood disturbance and other behavioral problems and can help prevent excess disability, health problems and functional decline. Adult day care plays an important role in the continuum of care, with the potential not only to delay nursing home placement, but to also reduce hospitalization and other acute healthcare costs.

≡ Increase the Office of Rehabilitation Services' Personal Assistants' reimbursement rate from \$5.52 per hour to \$7.02 per hour.

≡ Initiate a home and community-based waiver specifically for people with Alzheimer's disease and related dementias. Several other states, Florida and Wisconsin in particular, have such waivers with Alzheimer's disease and related dementia. The goal is to enable clients to remain independent in their homes longer and delay nursing home admission. This waiver provides services case management, adult daycare, respite, wandering-alarm systems, caregiver training, continence supplies, and personal care.

- ≡ Enact the Family Caregiver Act, Senate Bill 1620 and House Bill 1196.
- ≡ Increase the non-exempt asset limit for the Community Care Program (CCP) under the Department on Aging from \$10,000 to \$20,000.
- Provide quality training for dementia care. The single greatest factor of quality dementia care in all settings is the competency of direct care staff. In order to ensure quality care, the Alzheimer's Association supports innovative strategies to train qualified personnel in the home, the community and in licensed care facilities. The Department of Public Health and the Alzheimer's Association has been working on a dementia training manual in response to Public Act 91-744, which requires the development of criteria for training people to provide healthcare and home care to people with dementia-related disorders, and to assess the effectiveness of those people by certifying them. The department should reproduce and widely-distribute this manual.
  - ≡ Provide dementia specific training for direct care staff. The goal should be at least 20% of all required training should be refocused on dementia-specific issues.
- Improve quality assurance. The General Assembly plays a major role in determining the quality of care that people with Alzheimer's disease receive, whether or not the state is paying for that care. The Alzheimer's Association wants to ensure essential protections and opportunities for people with dementia in the codes that regulate all settings.
- Increase staff minutes paid for by Medicaid, using the MDS criteria, to adequately reimburse for the care of residents with Alzheimer's disease. That new payment methodology should also recognize that, while the condition of people with dementia may not improve, their quality of life should be maintained, and their care deserves equitable reimbursement.
- Restore the \$1.65 million for the Alzheimer disease centers, including Southern Illinois University, Rush-Presbyterian/St. Luke's and Northwestern. This funding supports a variety of clinical, educational and research programs that improve the lives of thousands of older persons and their families each year and bring millions of dollars to the state from the Federal government.
- Restore funding for the expenses relating to the oversight and licensure of assisted living establishments. A strong licensure code is needed to ensure the safety of the residents. Licensure without enforcement is meaningless.
- Support passage of the Dementia Special Care Unit regulations, which is going to be facing JCAR relatively soon. The 90th General Assembly enacted related legislation. It's important to add Alzheimer/Dementia Special Care Unit items under the special treatments and programs on the MDS. Research has shown that the most significant distinction between regular and specialized care units for residents with Alzheimer's or dementia is the increased staff time residents on the specialized units received for their care. Only programs on file with the Department of Public Health under the Alzheimer's Program Disclosure Act should be reimbursed under this item.
- Continue to work to support family councils that are present in long-term care facilities, and also expand those out to assisted living establishments.

The United States healthcare system is about to implode, and Alzheimer's disease is going to be the detonator. At the federal level, Alzheimer's disease is an epidemic that is already driving Medicare costs out of control. At the state level, Medicaid is just as vulnerable. Nearly 60% of nursing home residents are there because they have Alzheimer's or another form of dementia. The same holds true for the explosive growth in assisted living. Half of all Medicare beneficiaries with dementia also receive Medicaid because they have exhausted their own resources paying for that care.

By 2010, Medicaid expenditures for persons with Alzheimer's will increase by over 80%, to \$33 billion. Even though families provide nearly 70% of Alzheimer's care, no sector of our economy, public or private, escapes. Alzheimer's disease cost American businesses \$61 billion last year, twice as much that was estimated just four years ago, an amount that's also equivalent to the net profit of the ten Fortune 500 companies. This is just the beginning. It will get much worse. As the baby boomers enter the age of greatest risk, Alzheimer's will become the public health crisis of the 21st century. By the middle of the century, the number of new cases will increase by nearly 1 million each year. We are in a race against time. It is a race that we can win, but only if we work together to find appropriate solutions for the dilemmas that we're under today.

## **WENDY MELTZER**

ILLINOIS CITIZENS FOR BETTER CARE

---

Illinois Citizens for Better Care (ICBC) has 2 interests with respect to long-term care:

- that people who do not "need" to be in a nursing home are not forced into institutional living by unnecessary and artificial barriers, and
- that people who do live in nursing homes receive competent and appropriate care and services, and have decent lives.

It is important to understand that nobody "needs" to go into a nursing home. Entering a nursing home is a socioeconomic decision, not a medical one. If your last name is Rockefeller, you will never "need" to go into a nursing home. Usually, when we speak of somebody "needing" to enter a nursing home, we mean that they are so sick that they can only be taken care of in an institutional setting. In Illinois, however, this is not the case. Illinois, perversely, has been committed for years to acting as if it were the State of Rockefeller, using the Medicaid program to subsidize nursing homes by giving people who need much less than total nursing care, no choice but to move into a nursing home, even when staying home is cheaper — sometimes by half or more — than helping those people stay home.

Forcing this non-choice on people is fiscally and morally irresponsible. Illinois does it by artificially capping the number of hours available for the home care that the Department of Public Aid and Department on Aging will pay, even when we could pay for more hours at a decent wage, and still pay less than the state's current share of nursing home care.

At a minimum, Illinois should be making it possible for people who want to stay home to do so, when staying home would cost no more than nursing home care.

This is a partial list of how to do this:

- Revise the formula used to determine for how many hours of home care the state will pay for people over 65, so it is an honest comparison of home care *versus* nursing home care for each individual. When Illinois initiated its Home/Community Care waiver, we were paying for 8 to 10 hours of home care a day for people. Paying for that many hours was still cheaper than paying for nursing home care. We now pay for 4 hours a day. This isn't because nursing home care has gotten cheaper in comparison to home care. In fact, the opposite is true. It's because the formula has been distorted to artificially lower the number of hours for which people are eligible. This formula, and the assessment process, need to be made honest, again.
- In saying this, we recognize that the "woodwork effect" is real. If Illinois starts paying for the maximum number of hours of home care that are theoretically cost-effective, we can anticipate families, who are now paying for this care themselves, or doing the care themselves, applying for the state program with no savings at all to the state. Instead of capping the hours at the theoretical maximum, Illinois should be exploring creative use of the Medicaid waiver to help families who are caring for their relatives: For example, the state would pay for one hour of care over 6, for each hour the family paid for, or provided care directly, up to some maximum.
- Expand the availability of adult day care, especially for people who are incontinent. Expand the availability of accessible transportation to and from adult day care. This can be done, not by buying a lot of new accessible vans, but by facilitating dual use of existing accessible vans owned by, for example, day training programs and nursing homes.
- We know that there is a shortage of affordable, accessible housing. Of course we need to build more. But we also need to make better use of the housing we already have. Illinois should expand the number and breadth of its existing home-sharing programs, both for full-time residences and for day-time only care, so elderly adults can be cared for while their family members are working. Take a lesson from the Cook County Public Guardian, who keeps some of his wards out of nursing homes by having 2 or 3 share an apartment and split the cost of housing and personal care. Tie home-sharing into the Assistive Technology project, and existing Medicare funding for occupational therapists, who can do home visits, assess individuals, and make recommendations about what equipment and home adaptations can allow disabled elderly people to stay home safely.
- Create a central clearinghouse of available services, especially housing, with supportive services and personal care services. ICBC is already doing this, in a small way. We would be happy to show others how to do it.
- Put supportive services into existing senior housing, such as Chicago Housing Authority (CHA) senior buildings. There are obvious economies of scale in coordinating emergency call systems, chore and housekeeping services, meal services, and personal care.
- Make the services available under the Medicaid waiver programs uniform for all groups. It simply makes no sense that the waiver program will train family members of some groups of people how to care for their relatives, but not others, or do home-adaptation for only some people.
- Work with high schools that require community service credit for graduation, to refer students to programs that do shopping and home-delivered meals for home-bound people.

- Make doing home care, and working in equivalent programs — day training, adult day care — more attractive, by providing health insurance to the people who do this work. The most obvious way to do this would be by incorporating them into the state system.
- Stop using nursing homes as housing of last resort, sticking people in them because there is no place else to go. There are 12 thousand people with chronic mental illness in Illinois nursing homes. Probably half do not "need" to be there. They are there because the federally-mandated PAS (pre-admission screening) of chronically mentally ill persons is routinely falsified by screeners, who understand that the alternative to entering a nursing home is sleeping under a bridge. These people need hope. They need a life. They are in nursing homes, because the facility owners have made political contributions as an investment — thus far, a very successful investment — to make sure that their residents stay put. Illinois no longer has the money to pay off those investments. Illinois is also putting parolees into nursing homes, some of them with histories of committing violent crimes. Most of them belong in half-way houses, not nursing homes. Nobody should have to check the sex offender registry when picking a nursing home for their mother.

The difficulty with doing all these things is that we will decrease our nursing home population even further. We are now at 80% occupancy for facilities open at least a year. Do all these things, and we could be down to 60%. While this would be wonderful for the people who get to stay home, it would be a disaster for those who remain. Illinois nursing homes are already woefully understaffed, and the quality of care — actually, the quality of life — in far too many homes reflects that understaffing. Fixed costs remain the same: staff, food, supplies: Keeping open the same number of nursing homes, with fewer residents, residents who are sicker, have less involved families, is a recipe for disaster. Every bit as important, as keeping people out of nursing homes who neither want nor "need" to be there, is doing a much better job of caring for the people who remain.

These are some of the things what need to be done:

- Illinois needs fewer nursing homes, and fewer nursing home beds. As a general rule, Illinois should require a minimum occupancy rate to participate in the Medicaid program. There have to be exceptions to this in rural areas, where closing a nursing home would mean that families would have to travel unreasonable distances to visit their relatives. When exceptions are made, the priority should be on funding the county homes, and the not-for-profits, at least those not-for-profits that agree to admit residents on Medicaid. These are facilities that are putting money into the home, not taking it out, are more likely to have volunteers, and are more likely to have community involvement.
- Increase the number of Public Health nursing home surveyors. So many have taken early retirement, the department has lost its ability to do thorough complaint investigations, or initiate surveys of facilities that have repeated serious violations. The Department of Children and Family Services was exempted from the hiring freeze because of the importance we place on our children. Our grandparents should be treated with equal concern.
- Expand the Illinois Department of Public Health (IDPH) legal staff, so that the department does not feel pressured to settle cases because it does not have the staff to try them.
- Inform families and guardians of residents when a violation occurs in a nursing home that affects them. IDPH has promised to do a rule change that accomplishes this; it has yet to happen.

- Teach families of residents how to help their relatives when they move into a nursing home, including what nursing homes' obligations are to their residents. Tie this into the universal prescreening.
- Especially since Medicaid reimbursement is going to be based on the Minimum Data Set (MDS), we need to be checking on the accuracy of the information nursing homes enter in the MDS. Nobody does that now. Even the annual Public Health survey is a small, weighted sample of residents. It is unconscionable to pay out so much money with no real check on where it goes.
- Future Medicaid rate increases should be "targeted" — that is, their use restricted — to salary for direct care staff and food.
- While in some ways the IDPH website is helpful, the majority of nursing home violations are not posted, despite the legal mandate that they be there. IDPH should either do the work itself, or contract with an entity able to do the job.
- Strengthen the ombudsman program. In some areas of the state, the ombudsmen are vigorous resident advocates; in others they are no more than friendly visitors.
- It would improve residents' lives if high school mandatory service programs expanded to include having students assigned to specific residents and visit them regularly.
- The Office of State Guardian (OSG) needs both the resources to spend enough time on all its wards, and the mandate to function with the same vigor as would any private guardian concerned with a ward's welfare. Unless things have changed very recently, OSG is not permitted to pull its wards out of a nursing home unless it is actually being decertified or closed. It never uses what should be its considerable clout to force improvements the facilities that house its wards. These policies should be changed.
- Increase the personal needs allowance. Nursing home residents on Medicaid are allowed to keep \$30/month of their own income. Everything else goes to the nursing home. This has gone up \$5 in thirty years. If the personal needs allowance had kept pace with inflation, it would be over \$90/month. What this means is that every Social Security cost-of-living increase residents should be receiving, goes to supplement the Medicaid budget. Residents are left unable to buy shoes, buy a winter coat or underwear, a newspaper, stationery. They cannot afford public transportation, go to McDonald's, or go to a movie.
- Care in nursing homes will improve only when the people working in them feel personally obligated to do a good job. The CNA abuse/neglect registry is at least an attempt to hold CNAs liable for poor care. There is nothing comparable for people higher up on the food chain. The Department of Professional Regulation does not even open files on the large majority of referrals the Department of Public Health makes to it, of medical professionals and nursing home administrators who appear to have violated their responsibilities under the Nursing Home Care Act. Public Health does not bother to make referrals of mandatory abuse/neglect reporters who ignore their legal obligations.

*What this means in practice is illustrated by the situation at Chateau Village in Willowbrook, where numerous women in the Alzheimer's unit were repeatedly sexually assaulted over a 16 month period, by 2 male residents who were housed on the unit even though they did not have dementia. The staff*



*documented the assaults, but nobody reported them to Public Health, or to the police. Public Health finally found out, and the abuse finally stopped, only because an outsider witnessed one assault. The Illinois Department of Professional Regulation's (IDPR) response was to suspend the license of the Director of Nursing for one month. No other employee was disciplined. Nobody was prosecuted for facilitating the assaults, or even for failing to report them.*

It sounds absurd to say that the Department of Professional Regulation should be doing its job. We don't know what else to say. Public Health and the Attorney General should be training state's attorneys, sheriffs, and local police departments about criminal laws relevant to protecting nursing home residents, including the accountability provisions of the Criminal Code, and mandatory reporting requirements. Public Health should be working with the Hospital Association to train and retrain hospital employees (especially emergency room personnel) about mandatory abuse/neglect reporting laws.

**STEVE PITTMAN**

ILLINOIS ALLIANCE FOR RETIRED AMERICANS

---

Long-term care should be one complete system, regardless of how much or how little care a person needs, or from what kind of site care is provided. As folks get older, some people need a lot of care for a little bit of time. Some people need a little bit of care for a long time. Some need combinations in between. Folks should be able to receive the kinds of care that they need, when they need it, for as long as they need it. Care should be high quality. Whoever is providing care needs to be accountable. There should be oversight and quality assurance.

If the long-term care system is going to treat seniors with respect, workers and caregivers have to be treated with respect. Workers should be able to make a living providing care, and should be provided basic employee benefits, including health insurance.

The Long-Term Care Ombudsman Council now connected to the Ombudsman office will go a long way in creating greater independence and more effectiveness for that program.

Raising the community care program asset limit is also a priority.

The Health Care Justice Act would help the long-term care system, if we had universal health care in this country and in this state. The House has passed that legislation and it's sitting in the Senate.

**SHIRLEY KELLUM**

STEWART SEIU – SERVICE EMPLOYEES INTERNATIONAL UNION

---

House Bill 1179 was much needed. It granted personal assistants a two-dollar raise [Note: This bill was Vetoed and died during the 2003 Fall Veto Session of the Illinois General Assembly.].

House Bill 2221 was also supported by SEIU, which granted 2100 personal assistants collective bargaining rights with the State of Illinois. SEIU hopes to be soon signing a contract that will

increase personal assistants' wages by \$2.35 over a four-year period. Workers will go from seven dollars to \$9.35 and have a Union contract with additional benefits.

House Bill 1178 — passed the House, currently in the Senate Rules Committee — increased the rate for the Department on Aging workers. There are about 18,000 homemakers, the majority of which are making less than \$6.50 an hour.

Caregivers need to make more than six dollars an hour. They need health insurance.

The Home Services and Community Care Programs are important. They are getting more important, as the population gets older and wants to stay in their homes. We've got to invest in this program, because this not the type of job where you can hire just anyone. This is a job for the person that wants to take care, wants to spend time taking care and the person that you would want to take care of your mother or father.

We need to stabilize the home care workforce to make sure that seniors have the kind of programs that they deserve.

A year from January, the majority of home care workers in the Community Care Program will need a \$.75 cent increase just to be at minimum wage and to be in compliance with the law. We are proposing an increase of at least one dollar an hour to provide parity with the Personal Assistants' rate and move workers towards a living wage. This rate increase should go directly to the workers and not to the company that hires the worker. The worker needs the raise. This should not have to be bargained with each employer. Give the worker the dollar.

Finally, home care workers need health insurance. They are primarily older, single women. Their kids are out of the house, and there fore not eligible for Family Care. They are too young for Medicare. A survey of home care workers found that those who are uninsured miss more work because they get sicker, and they use emergency rooms and county hospitals and spend unnecessary time waiting just to get medication, while unable to provide services to our clients.

Home care is cost effective and provides seniors with the kind of care that they want. We should expand this program while investing in the kinds of wages and benefits that will ensure a quality workforce for Illinois seniors

## **RODERICK BASHIR**

SERVICE EMPLOYEES INTERNATIONAL UNION, SEIU

---

SEIU Local #4, with 8,000 members, believes that there should be a career ladder program for certified nurse aides, which would allow nurse aides to receive advanced training, while enabling them to reach higher levels within their profession.

SEIU also believes that there should be a nursing scholarship program, in which the state would dedicate 20% of its existing nursing scholarship programs for individuals who want to work in long-term care.

Funding of the long-term care system in Illinois is the most pressing issue. The long-term care industry should be funded. Funding cuts that have taken place should be returned to the industry. Inadequate staffing has led to widespread violations of federal care standards.

The SEIU report, *"Facing a Crisis in Care,"* found that Illinois nursing homes were cited for 3,168 violations of federal resident care standards. Seventy-eight percent (78%) of nursing homes inspected have been cited for violations that put residents at risk. Many of the violations were due to insufficient staffing.

Low nursing staff levels correlate with a greater likelihood that residents will not be fed properly, turned or re-positioned frequently enough, bathed and groomed adequately, or exercised to ensure that they retain adequate range of motion. In such cases, residents lose weight, become dehydrated, or suffer from deterioration. In 2002, 86.5% of Illinois nursing homes were unable to reach the staffing levels recommended by the federal government. Last year, Illinois ranked last in the nation in nurse aide hours and next-to-last in total nursing hours.

Low staffing results from low wages and inadequate training. The median pay for certified nurse's aides in Illinois in 2002 was \$9.51 an hour, or \$19,781 annually, or an income that qualifies a family of four for food stamps and public housing. The low pay and lack of benefits contributes to high turnover for caregivers. In 2002, the annualized turnover rate for certified nurse assistants (CNAs) in Illinois was a whopping 75.5%. The high turnover rate threatens to compromise the continuity of care and makes an already challenging job harder for the caregivers who stay.

Staff training is also inadequate. Certified nurse aides (CNAs), who provide 80-90% of the direct care, are only required to get 120 hours of training.

The most recent research shows that Illinois ranks 49<sup>th</sup> in the nation in Medicaid reimbursement, behind only Louisiana. According to a 2002 study by BDO Seidman, Illinois pays less than the cost of care for its Medicaid residents. The report concluded that it costs \$8.12 per resident per day more than the State provides, which leads to an annual shortfall of \$156 million a year.

In 2002, the state cut nursing home rates by 5.9%, or approximately \$116 million, while the cost of care continued to increase.

Recently proposed changes to Illinois' Medicaid reimbursement system could worsen the quality of care in Illinois in the nursing homes as well. Although the measure proposes setting minimum staffing standards above current levels, it also proposes capping annual funding for nursing homes. As a result of the cap, individual providers would face unpredictable rates that would decline whenever overall statewide acuity increases. Limiting the money available for additional staffing would force nursing homes to cut wages by approximately 20%, making it even harder to attract and retain quality staff.

To provide the quality of staff in Illinois nursing homes, funding for care must be increased, not decreased. More funding would mean higher wages and benefits for caregivers. It would also go a long way toward reducing the turnover and improving staffing levels for residents.

SEIU recommends:

- Restoration of the 5.9% cut to the Medicaid reimbursement rate; and
- Restoration of the provider assessment to its previous level of 6%, but put the proceeds in a quality care improvement fund to attract more medical matching funds for care. The assessment would generate approximately \$327 million. These funds should be used to increase wages, benefits, and training for nursing home workers.

Failure to take these actions would mean that some of Illinois' most vulnerable citizens will spend months, if not years, living in increasingly worsening conditions, and the crisis of care in this state will continue.

## **BILL KEMPINERS**

ILLINOIS HEALTHCARE ASSOCIATION

---

Illinois must engage in a comprehensive planning effort. This effort must include attention to regulations and their relationship to quality care. It would be ideal if there was a new environment in which providers are encouraged to deliver the highest quality of care rather than discouraged by the current system of sanctions, fines, and other punishment. Illinois must develop a new system that clearly defines the expectations, pays appropriately for meeting or exceeding those expectations, and severely punishes those who knowingly or willfully do not meet the defined standards. There are bad providers. Those entities must be shut down.

### ♦UTILIZE LONG-TERM CARE FACILITIES TO PROVIDE NEEDED COMMUNITY SERVICES

Long-term care facilities already exist in most communities, and long-term care occupancy rates have decreased as alternative settings have been developed. In fact, in many downstate communities the long-term care facility is the only health care entity, and the largest employer. As these facilities already exist, they should be put to maximum use by expanding the services that can be provided in and through these facilities. Capital costs related to these uses would be far less than building a new, freestanding structure.

These existing facilities could be used to meet many community needs, in addition to continuing their long-term health care mission. Long-term care facilities operate 24 hours per day, 7 days per week and 365 per year. They are always staffed, and therefore may be able to provide multiple services to caregivers, seniors and the disabled, including but not limited to the following:

- Adult day care
- Senior centers
- Home health care
- Personal response systems monitors
- Transportation
- Congregate and carry out (special diet) meals
- Tele-nurse services
- Meals on Wheels
- Caregiver support and training services

To take advantage of this valuable resource, changes must be made in state and federal regulations, or waivers must be sought.

### ♦PROVIDE INCENTIVES TO ELIMINATE UP TO 50% OF UNOCCUPIED LONG-TERM CARE BEDS

The statewide long-term care occupancy rate currently hovers at about 82% for several reasons. There is a cost to the state for unoccupied beds, as part of the cost of caring for Medicaid residents. Therefore, it is in the state's interest to provide a financial incentive to providers willing to give up some of these empty beds. However, as some of these unused beds may be needed, as baby boomers reach their 70's and beyond, long-term care providers should be given the financial incentive to "bank" at least some of these unoccupied beds for a definite period of time. If there is a need to reopen the beds within a certain time period, the provider would lose a portion of the incentive originally received. Incentives could also be

offered to facilities to convert multi-bed rooms into single rooms, which would better meet the expectations of seniors and the disabled. Most are used to living independently and this would relieve some of the additional stress associated with entering a facility. Several states that have implemented such incentive programs successfully, including Minnesota.

♦FULLY IMPLEMENT THE MDS-BASED REIMBURSEMENT SYSTEM

This legislation was implemented July 1, 2003, although the legislature did not provide the additional funding necessary to accomplish the purpose of the legislation.

We ask for the continued support of the legislature as we move through the rule-making process and begin the two-year transition to a Medicaid nursing reimbursement system in which the dollars will more closely follow the needs of the patients.

♦ENSURE FAIR AND REASONABLE OVERSIGHT OF ALL TYPES OF LONG-TERM CARE FACILITIES

State budget cuts and early retirements have significantly depleted the resources of the Illinois Department of Public Health, the agency charged with regularly conducting oversight of licensed long-term care facilities, assisted living establishments, and unlicensed entities. This has stretched existing staff beyond reasonable limits. Further, the majority of the dollars designed to establish a survey unit for assisted living and supportive living facilities was eliminated from the budget approved by the Governor. These situations may result in additional stress to the oversight system in Illinois.

It is important to ensure that high quality and consistent surveys will be conducted by a team of well trained surveyors/reviewers that the elderly and disabled have access to licensed entities, and that unlicensed entities are inspected and, where necessary, closed. This requires the availability of appropriate human and financial resources.

♦BE CAUTIOUS ABOUT MEDICAID PROVIDER TAX PROPOSALS

Increasing provider taxes has been advanced as a possible solution to increasing funding for long-term care. Geriatric facilities currently pay a provider tax of \$1.50 per bed per day, and facilities for the developmentally disabled pay 6% of net revenue (the maximum allowed by federal law). The dollars raised through these tax programs receive federal match.

Long-term care facilities are the only providers who pay such a tax, although a hospital tax is currently under consideration.

Last spring, there were some initial discussions about increasing the existing geriatric provider. Although increasing provider taxes may seem like an easy solution, the legislature and administration should be cautious about implementing such proposals. The financial condition of nursing homes is unstable. Significant increases in existing taxes would be very difficult to manage. Facilities are juggling mortgage payments and food bills, working closely with creditors to manage their limited resources. Proposals to distribute new tax dollars in an across-the-board rate adjustment (the usual way of distributing the tax dollars), would be inconsistent with the provisions of House Bill 5567, which mandates that new dollars be used to fund the MDS-based nursing reimbursement system.

Bed or provider tax proposals should be analyzed closely. All funds generated by a provider tax should be earmarked to increase the reimbursement levels of that provider group and, if there is any general tax increase, providers should be immediately relieved of the provider tax burden.

Representatives of all provider groups affected by the tax should be at the negotiating table as any provider proposal is considered.

If additional taxes are considered for any provider group to fill a budget hole or to increase funding, such a plan should be considered for all qualified Medicaid provider groups.

♦RATES SHOULD BE BASED UPON A UNIFIED, OBJECTIVE, VERIFIABLE, COST BASED REIMBURSEMENT SYSTEM USING AUDITED PROVIDER COST REPORTS

It makes no sense that some providers receive more than their costs, while others receive less than the cost of providing care. Some receive a huge “profit” (up to 27% in some cases), while others do not. As part of a comprehensive planning approach, the state must be able to know what each service costs, and pay providers fairly based upon those costs. Unfortunately, cost information is currently not collected from some groups; while for other it is collected, but not used to establish payment rates, and there are no negative consequences if providers do not submit the information.

♦ESTABLISH A STANDARDIZED COMPLAINT SYSTEM

An important aspect of ensuring customer and family satisfaction is the ability to make reasonable complaints and to have those complaints resolved. The current system makes it difficult for an individual to navigate through the complaint process. Currently, IDPH, IDHS, Aging, and the State Police all have complaint hotlines. Individuals contacting these hotlines may not be aware of the appropriate agency to contact when problems arise. Consolidation of these hotlines into a single entity will streamline the process, saving vital time and state resources as well as making the complaint process much easier to access. In addition to a common intake system, it is imperative that common definitions of abuse, neglect and financial exploitation, common complaint investigation procedures, common definitions of types of complaints, standardized mandated reporter guidelines and standard complaint investigation protocols be established.

♦ESTABLISH A WEBSITE THAT CONSUMERS CAN USE

The website must be searchable and user friendly. It should include an assessment tool to gauge the needs of the prospective customer, an explanation of the costs of the service options, and a directory of the full range of services available by geographic area. As the site is developed, it could be expanded to include the results of customer satisfaction surveys, quality standards, staffing information, and comments from residents and family members about the service delivered in each setting so that individuals searching the site can get a balanced view. It would be necessary to determine the most appropriate state entity to host and maintain the site, dialog with interested parties about the content of the site and give consideration to what consumer satisfaction information should be contained on the site and the most appropriate method for collecting such data.

♦DEVELOP A SINGLE POINT-OF-ENTRY FOR ALL LONG-TERM CARE SERVICES, AND CONSOLIDATE CASE MANAGEMENT SERVICES

Right now individuals spend considerable time just learning how to navigate the system. Many become frustrated and finally enter the system with negative attitudes about how they have been treated. Dealing with health issues of family members is stressful enough without complicating it further. The unification of case management activities would benefit customers,

providers, and the state by streamlining the process. Any such process should ensure the fair representation of all types of appropriate services available to the customer, disclosure of the estimated costs of those services, and a clear determination of the personal, health and medical needs of the customer.

♦STANDARDIZE TRAINING, BACKGROUND CHECKS, AND OTHER REQUIREMENTS FOR CAREGIVERS

Currently, a number of state agencies are responsible for licensure, employment, or pay for caregiver services, including the Illinois Departments of Public Health, Human Services, Public Aid, and Aging. Standardization of caregivers requirements will save state resources and allow caregivers to easily shift their services along the continuum as necessary or as they desire.

♦IMPROVE WORKING CONDITIONS AND OPPORTUNITIES FOR ADVANCEMENT FOR WORKERS

This can be accomplished in part by the following:

- Allow long-term care employers to purchase health insurance for their employees through the state employee insurance program. Such proposals in the past have met with considerable resistance from the Illinois Department of Central Management Services. Economies of scale make such insurance less costly than purchasing small group policies and more affordable for financially strapped entities.
- Establish career ladder programs that are available for all employees. All entities must have the ability to create these programs and fund the financial incentives provided to employees.
- Explore possibly allowing unlicensed personnel to distribute medications in long-term care facilities and assisted living establishments under the supervision of a licensed nurse.

♦INCREASE THE NUMBER OF CITIZENS COVERED BY LONG-TERM CARE INSURANCE

There have been attempts in the past to create some incentives for the purchase of long-term care insurance. But, frankly, the incentives proposed in past legislation have proven to be of little benefit. Illinois needs to get serious in its approach to these incentives, so that the average citizen will be encouraged to explore the benefits of such coverage. The state, too, must do a better job of marketing long-term care insurance to its' employees and their families.

♦IMPLEMENT THE QUALITY IMPROVEMENT GRANTS PROGRAM

This program includes a commission to review quality initiatives submitted by long-term care facilities. Monies for the program will come from fines and penalties paid by facilities for non-compliance. The federal government has already indicated that programs of fines and penalties may be used in creative ways, and this could be structured to meet the federal requirements. Regulators, advocates, and providers should work together to develop such a program to improve the lives of individuals living in Illinois' nursing homes. The lessons learned through the implementation of these quality initiatives may be transferable to other homes as well.

## TERRANCE SULLIVAN

ILLINOIS COUNCIL ON LONG TERM CARE

---

There is a consensus emerging through this Summit on Long-Term Care. Nursing home care needs to be better-integrated and supportive of the continuum of home and community-based care; and no one wants to see the quality of care in nursing homes go downhill. That is a good two-pronged approach.

There is consensus that there should be a single source for case management and central referral system; a consistent patient assessment system; a universal licensing system; and an active, acuity-focused, patient-centered reimbursement system across the entire continuum of care.

Wherever a person is placed, they should have the same accountability, the same funding based on their needs, and the funding should follow the patient in whatever setting. The right person should get the right amount of care in the right setting for the right funding.

The council provided a detailed statement at the regional meetings, a summary of which is attached to this report.

\* \* \*

There's been considerable discussion about a provider assessment and how it's raised. If we follow the federal limit, we're probably talking about raising 160 million from providers and 160 million federal matching funds, or about 320 million. There's been considerable discussion on how to structure the tax, so that as few private pay providers as possible would not be covered. If a facility accepts Medicaid residents, they would probably have to pay the tax, even if they are 20% Medicaid and 80% private pay. So it's going to hit everybody.

In terms of the distribution of the assessment revenue, the heart of the discussion is about what gets funded with the \$320 million. I don't think anyone has decided that, yet. Nursing homes would be asking for \$320 million as a starting point, but there are different opinions on how that might get spent.

The council would like to see increases in home care; increases for nursing home care; and certainly restoration of the 5.9% cut in rates effective in state fiscal year 2003 before anything else. The remainder could provide more home and community-based services. It could cover the cost of the "MDS" (Minimum Data Set) reimbursement system. It could provide quality of care incentive grants. It could be for career ladders. The advantage would be that these improvements could be implemented without any additional cost to the state General Revenue Fund. The details would have to be worked out by the legislature, including assurances that this new money is not reallocated to supplant General Revenue.

In terms of cost shifting, whether it's a provider assessment or a rate cut, costs now get shifted to private pay residents. When there is a rate cut, when state and federal funding is lost, there is far more cost shifting to a private pay resident than if we have a provider assessment. A provider assessment is the best way to bring in federal funding with the least amount of cost shifting to private pay residents.



**STEVE NUSSBAUM**

LIFE SERVICES NETWORK, WINCHESTER HOUSE

---

Illinois needs a comprehensive plan; and a single-point-of-access. There needs to be oversight across the entire spectrum of services to make sure that each portion is adequately observed at all times.

Illinois needs a quality assurance component that is unified across the entire spectrum of care.

There is also a need for staff programming to ensure that we have a sufficient quantity of both Certified Nurse Assistants (CNAs) with a career ladder, as well as a sufficient quantity of nurses.

Legislators are going to have to think long and hard about money. Maine and Minnesota have daily reimbursement rates for Medicaid for long-term care well in excess of what is provided in Illinois. In 2001, the average daily reimbursement rate in Illinois was \$90.06 a day. In 2001, in Maine, that same provider was getting \$119.60, and in Minnesota, \$123.18. Those states had to shift some money to community-based services. Illinois is nowhere near close to getting adequate reimbursement for the services provided.

A comprehensive program needs to have all components, but should not be implemented until all are present. Until that point, there should be a bridge of funding to help the existing programs keep going until that comprehensive plan is completed. One example is the “FMAP” money — the additional \$356 million from the federal government — that is not yet obligated. This Medicaid money should be going to medical programs.

It is important that Illinois honors the seniors of the state, by making a full effort to make the long-term care system successful.

**KELLY SCHLEICH**

ADULT DAY SERVICES

---

Illinois Adult Day Services Association expresses its appreciation for this summit and regional meetings.

**KAREN CRIPPS**

ILLINOIS ADULT DAY SERVICES ASSOCIATION

---

The Illinois Adult Day Services Association has approximately 75 members and serves approximately 3,500 participants statewide.

The association appreciates the advocacy that assisted in the reimbursement rate crisis, which was addressed by a recent increase.

There is still a crisis. According to the Robert Wood Johnson Foundation's national study, Illinois needs 277 more adult day centers. At the time of that study, there were 88 centers. There are currently 76 counties in Illinois that are underserved. That means there is 1 center, possibly 2 centers, and they are not adequate to meet the needs of the people in those communities. There are also currently 62 counties that do not have a center. Approximately 24% of the contracted adult day centers closed within the last three years. The recent rate increase may stem that tide and bring new providers onto the program so that more seniors can have this option. Additional rate adjustments are necessary. A more equitable rate is required. The reimbursement rate that was approved was a great step, but it is still not at the cost of care determined about a year or two ago through a survey.

An increase in the asset level for the community care program is also necessary, as well as elimination of the co-pay under the Community Care Program.

**ANN DERRICK**  
HOME CARE COUNCIL

---

Skilled intermittent home health services are different than those provided by the personal assistants to the disabled or the Community Care Program workers. These home visits are prescribed by a physician, and are medically necessary to serve the people of all ages who are usually homebound. It includes seniors and children. Services include skilled nursing, PT (physical therapy), OT (occupational therapy), speech, and home health aide services.

The state should remember to use home health services. Home health providers are the most forgotten and untapped resource in this state. There are over 10,000 Registered Nurses (RNs), probably several thousand occupational therapists, speech therapists, physical therapists that are available, that are already out there serving a lot of the seniors in the community.

Home health providers are frequently forgotten, because most of the funding is provided by Medicare, and not a lot on state funding. For complex patients, home health providers can help provide a bridge as they move from hospital back to home, or even from nursing home back to home. RNs can provide training and medication management to the caregivers that are going to be in the home. Occupational therapists can come in and make home modifications, or teach basic Activities of Daily Living (ADLs) to help improve the quality of life at home. For more complex patients at home, home health providers can become the 24 hours per day, 7 days per week service.

**ANN FORD**  
ILLINOIS CENTERS FOR INDEPENDENT LIVING

---

In 2002, there were over 12,000 people in nursing homes throughout Illinois between the ages of 18 and 59 who were not elderly, but who had disabilities. For the most part they didn't need to be there.

The pre-screening process needs serious review to determine how it is that people inappropriately wind up in nursing homes.

We have a program that many of our centers participate in that's a community reintegration program that works with people with disabilities to move them out of nursing homes. There are disturbing stories among these cases that demonstrate how some placements occur. One person had severe asthma and had one attack that landed her in the hospital. She didn't have air conditioning in her apartment, and rather than just look for a way to get her an air conditioner, she was put in a nursing home.

A young man who suffered a spinal cord injury in an accident ran out of health insurance coverage for his rehabilitation. This particular young man had been waiting 5 years for that rehab and it never came.

There is something missing in how we decide who goes into a nursing home. One of the things that the people who make decisions and policies in our state need to understand is that having a disability is not the same as being sick. With the right kind of services and supports, if you have a disability, you still can go out and have a very productive life. That might mean you need a personal assistant, who comes in and lifts you out of bed every morning and gives you a bath, but you still can do it.

If you're 25 and you wind up in a nursing home, you tend think the same that it's the end of your life, because that's the mindset. You don't go to a nursing home to live. You go there to die. It doesn't matter how old you are. If that's where you wind up, and you are surrounded by people who truly are sick and are older, it's not long before you feel that same way.

Some of the problems in our system that we need to look at are things that would be much less costly than having somebody moved to a nursing home, including home modifications. Some aging people develop severe arthritis, or something that prevents them from being fully mobile. They may need a ramp on their house, or bars in the bathroom. It would make more sense to install these supports than to send these persons to a nursing home.

The disparity of services between people under 60 and over 60 is another thing. If a person is under 60, they may be able to hire a personal assistant that enables him, or her, to live at home. This means the person can continue to have a really good life. If you're over 60, this option may not be available. The person can receive homemaker services, or other supports, but not personal assistants. That option is no longer available when the disabled person is older than 60.

It's time to return our nursing homes to what they're supposed to be, and to take people who don't need nursing home care and let them live at home with the supports they need.

**DARCIA FERRARI**

ASSOCIATION OF ILLINOIS SENIOR CENTERS, PUTNAM COUNTY SENIOR CENTER

---

Many people do not know about senior centers. Senior centers encourage independent living for older adults. They offer educational, informational and recreational programs, health screenings, physical fitness, social services, hot meal programs, volunteer opportunities and employment opportunities for senior citizens. They also offer "circuit breaker" assistance, caregiver support, as well as linking seniors with many other agencies, such as alternatives for older adults and home healthcare. It is a very cooperative effort.

The Putnam County center loans medical equipment free-of-charge, and that service is for all ages. It has been an extremely important service.

Senior centers promote healthy aging and community involvement. The Putnam County Senior Center relies a great deal on volunteers. The entire staff is part-time, due to limited funds, so the volunteers are extremely important. The director is part-time. The entire transportation program is done by volunteers using their own vehicles and volunteering their time.

Putnam County is a rural county without any public means of transportation. There is no hospital, so there is no rehabilitation, chemotherapy, or radiation treatments. Those all have to be done outside the county, so there is a need to transport seniors outside the county to have that done. The center is transporting seniors several times a week, and some seniors are everyday transports. It's completely done by volunteer drivers.

There is only one grocery store in the entire county, so even getting groceries is an issue. It's a very, very important service for the seniors and for a lot of people in the area. There is a sense of isolation that seniors could feel, if these services were not available. That can be overwhelming, and many times can lead to depression. That is where the Putnam County Senior Center and many other senior centers come into play.

The outreach worker calls on the seniors in their homes, lets them know what services are available, identifies what services they need, and she checks on them. This is a link to the outside world. The center has helped seniors with just about any kind of problem imaginable. There have been calls at home from 6 a.m. on Sunday morning, to 10 p.m. on Friday night.

Hundreds of senior citizens come to senior centers each day, and they come for many reasons. They have been able to maintain themselves in independent living. They are aging gracefully and dealing with the changes with minimal support.

Senior centers promote healthy lifestyles and emotional well-being. The center's doors are open, offering a broad range of activities and services that meet older persons' needs. Many seniors will not need additional services, because the center is helping them meet basic needs. Seniors want to stay active and have choices. That is a big issue, having choices. The senior center gives them a place to go to and meet new friends and receive support.

Senior centers are the front line of preventative support to our aging population. They can spot changes, crisis and isolation before any other long-term care provider in the continuum. They can intervene early with information and support services to lift that senior out of depression and out of that isolation and crisis. Centers help seniors to maintain the lifestyles with dignity and respect, and that is an essential issue. Seniors want and need to feel that they still have some control over their own lives.

The Putnam County Senior Center is located in Standard, Illinois — a town with a population of 300. The center provides services for the entire county. Putnam County is the smallest county in the state, which means that it gets the smallest funding allocation. It received partial funding through grants from the Western Illinois Area Agency on Aging under Title III of the Older Americans Act. It is a free-standing senior center, which means it owns a building, and it's up to the center to maintain it and keep everything going, which is becoming more and more an issue and a problem, as it is with most senior centers across the state. In a very small county with very few resources, it is becoming more and more of a struggle.

Putnam County has 1,264 seniors, with a total population of 6,068 people. The seniors comprise over 20 percent of the population. The Putnam County Senior Center has provided assistance in the last year to 1,203 of Putnam County seniors, and assistance to another 396 seniors from outside the county who come to the center. That is a total of 1,599 seniors who have received assistance through the center in that very small community of only 6,088 people.

275 communities have senior centers offered through local government units and private nonprofit organizations. They serve 650,000 seniors annually and make independent living possible through nutrition, transportation, adult daycare, CCUs, ombudsmen, and assistance through the Senior Care and Circuit Breaker (prescription drug assistance) programs. Socialization programs are available to prevent isolation and nursing home residency.

There are 2.2 million seniors in Illinois. 100,000 are in nursing homes. 650,000 access services at senior centers, and that's with 275 senior centers. That leaves 1,450,000 seniors missing essential services, because they may not be able to get to a senior center. That's a lot of people that are being left out, and that is because the centers are all struggling to survive.

Centers do not have money for health insurance, nor for pension plans for their staff. Staff does not earn enough money to purchase that coverage independently. This low level of support is creating future clients. The same population will need assistance, because current providers are not earning enough money.

Senior centers play a vital part in services for seniors. Even little Putnam County, with a total population of 6,086 people for the entire county, has provided assistance to almost 1,600 seniors in the last year. Those statistics do not show all of the programs and other events and assistance that have been provided. This is all done with an entire staff being paid part-time.

Senior centers mean positive aging. Senior centers are the first step in the long-term care continuum. Senior centers deal with the needs of seniors daily. Senior centers are visible in the community, and older persons know that they are welcome to drop in, see what services and activities are available and join in.

## **VIRGINIA HARMON**

CONSUMER - PUTNAM COUNTY SENIOR CENTER

---

I'm 86 years old. I have belonged to the Putnam County Senior Center for 17 years. I've always enjoyed it. We have a lot of fun, but we have heartaches too. About four years ago I got the curse, you know — macular degeneration — and I was legally blind. When this happened, I thought my life was over. I couldn't imagine how I could go on living, not being able to read, to write. I was always very active, and I couldn't accept this (disability). It just threw me. I was devastated, so I went into a deep depression, and I landed in the hospital.

When I came out, the first person at my door was an outreach person (from the Putnam County Senior Center) and she insisted that I must come to the center. And I thought to myself: "What for? I'm just a lump. I'm going to sit there, do nothing and look for pity." She would not take "No" for an answer. For every excuse I had, she had a solution. To get her off my back, I went back (to the center), and I must tell you that was the most wonderful thing I could have done, because they gave me my life back.

Our director and her staff, all the seniors, it seems that your problem is their problem.

Darcia has a friend who teaches the blind. She has a little girl student who is going into a higher grade. She was going to sell a (special) video machine and Darcia brought it and showed us that our life wasn't over. There are a lot of things that you can do. I had never heard of anything like this. If I couldn't see, I was dead. I bought that machine, and it is wonderful. Now I can read my own mail, I can write my own checks.

I like to play bingo, and we play a lot of that over at the center. Darcia got me a great big bingo card. I couldn't see the little discs that we had on this great big bingo card, so one of our ladies, Virginia, crocheted (large) size markers for me. I can play bingo just like the rest of the people. I (now) win a lot of times.

They (also) found me a talking alarm clock, which flabbergasted me, because I never thought there was such a thing. I never was interested in things like that. I didn't have that problem. So that alarm clock is wonderful, because you just press the button and it tells you what time it is. The only problem is that it has an alarm, and it's a rooster, so I was blaming all my neighbors for having a rooster at 4:00 in the morning because I couldn't see that it was the alarm.

(I now have) talking books. That is the most wonderful, wonderful program for blind people that has ever been invented, and I hope it never disappears. I don't go so much for fiction. I like history, geography, biography, things like that. And I think I learned more since I've been blind than I had all the years I went to school.

There is another gentleman in my club who has the same problem I have, and he had his own medical supply business, and his own plane. When this happened to him, he was thrown for a loop, just like I was. He fell apart also, only he didn't turn to a doctor for help, nor did he go into a depression. He started to drink and, of course, when he hit bottom he called Darcia and tells her he's going to commit suicide. Well, there were two people in our organization who took him under their wings and they took him to AA. They took him to therapy, and they worked with him for quite some time. Although Mike is not the healthiest person, he (now) seems to be very happy these days, and even (with) that great big video eye, he even makes model airplanes, which just floored me, because I couldn't understand how he could do that.

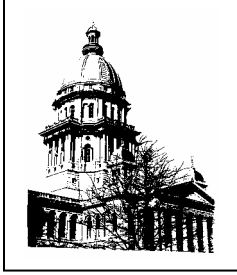
And then we have another couple, Tom and Alice. She was a lovely little lady. She had heart surgery. Two months, after this little girl had heart surgery, she had a stroke. Her entire left side was paralyzed. She came down in the wheelchair and played bingo with us, and tried so hard, but half the time she forgot what she was doing. It was hard for her. We all felt bad. When she graduated from the wheelchair to the walker, we celebrated. When she graduated from the walker to the cane, we were just thrilled to pieces. Anyway, this little girl at one time had cancer. I didn't know about that immediately, but she did. About six months after all this happened to her, her cancer comes back. Well, that was just a little too much for little Alice to handle. She threw in the towel. Her husband Tom kept coming to the center, but not as often. He was heartbroken. You know how it is when you lose someone. One day he calls the office and tells Darcia his furniture is all out on the street. They have repossessed his dwelling. He has no place to go. She had to find him a place. The workers do everything for us. It's wonderful. They found him a senior high-rise, but in the next town, and he's very happy. He still comes to the Putnam County Center.

On July 31, we were going to a dinner playhouse, and all the seniors are dressed to the hilt and all sitting in the bus waiting. The driver is there and the motor is running, and we couldn't find

our director. We went back into the building, and there is Darcia on the phone with another little senior, who was so upset because she's on a respirator and they were coming to shut off her electricity. Darcia wouldn't let the bus move until she got somebody to take over. She took care of it, and knew that this person was going to be all right. We went to our playhouse, and it was enjoyable. This is one thing we do at different times of the year.

We have different things. We have a bazaar, because we have to meet a certain amount of money. We all work like little beavers, baking and everything else.

This is what goes on sometimes at our end.



## SPEAKER'S SUMMIT ON SENIOR SERVICES

### LONG-TERM CARE

#### SUMMARY OF TESTIMONY AT REGIONAL SUMMITS

Thirty different regional summit meetings were held throughout the state. Representatives of various state agencies and organizations were invited to participate as panelists at each meeting, and also provide formal testimony. State agencies generally explained their role in the long-term care system. Other stakeholders and consumers provided additional testimony. All written testimony and summary memoranda from each meeting have been compiled. Recommendations submitted at those meetings by organizations or individuals are summarized or paraphrased in this report. This summary does not include all comments. General and duplicate testimonies are also excluded. The location and schedule of all hearings follows:

#### REGIONAL MEETINGS – LONG TERM CARE

DATE	REGION	SPONSORS
7/8	Belleville	State Representative Tom Holbrook (D-Belleville)
7/9	Northern Cook County	State Representative Elaine Nekritz (D-Northbrook)
7/15	Decatur	State Representative Bob Flider (D-Mt. Zion)
7/15	Southern Illinois	State Representative Brandon Phelps (D-Harrisburg)
7/15	Waukegan	State Representative Eddie Washington (D-Waukegan)
7/17	Chicago – South	State Representative Connie Howard (D-Chicago)
7/29	Effingham	State Representative Bill Grunloh (D-Effingham)
8/4	Aurora	State Representative Linda Chapa LaVia (D-Aurora)
8/7	Champaign	State Representative Naomi Jakobsson (D-Champaign)
8/12	Rockford	State Representative Chuck Jefferson (D-Rockford)
8/12	Vernon Hills	State Representative Kathy Ryg (D-Vernon Hills)
8/12	Cook County - Southwest	State Representative Kevin Joyce (D-Chicago)
8/14	Cook County – West	State Representative Karen Yarbrough (D-Maywood )
8/15	Cook County – South	State Representative Will Davis (D-Hazel Crest)
8/19	Moline	State Representative Patrick Verschoore (D-Milan)
8/20	Chicago – Northwest	State Representative Joe Lyons (D-Chicago)
8/21	Park Ridge	State Representative Rosemary Mulligan (R-Park Ridge)
8/21	Jerseyville	State Representative Jim Watson (R-Jacksonville)
8/22	Elgin	State Representative Ruth Munson (R-Elgin)
8/25	Naperville	State Representative Joe Dunn (R-Naperville)



8/26	Palatine	State Representative Suzanne Bassi <i>(R-Palatine)</i>
8/26	Bloomington	State Representative Dan Brady <i>(R-Bloomington)</i>
8/27	Cicero	State Representative Frank Aguilar <i>(R-Cicero)</i>
8/28	Madison County	State Representative Ron Stephens <i>(R-Troy)</i>
9/3	Downers Grove	State Representative Patricia Bellock <i>(Hinsdale)</i>
9/4	Williamson County	State Representative Mike Bost <i>(R-Murphysboro)</i>
9/8	Chicago – North	State Representative Sara Feigenholtz <i>(D-Chicago)</i>
9/9	Clark County	State Representative Roger Eddy <i>(R-Hutsonville)</i>
9/10	Wheeling Township	State Representative Sid Mathias <i>(R-Buffalo Grove)</i>
9/26	McHenry County	State Representative Jack Franks <i>(D-Woodstock)</i>

### **HEALTH AND MEDICINE POLICY RESEARCH GROUP**

#### **●Expand and enhance services available to seniors in the community.**

- Offer care plans that include services beyond the 2 routinely covered by Community Care Program (homemaker, adult day services).
  - ≡ Specifically add services that enhance family care giving.
    - ♦ Respite care.
    - ♦ 24-hour alert systems.
    - ♦ Transportation.
    - ♦ Caregiver advocacy and counseling.
    - ♦ Home modifications.
  - ≡ Coordinate Community care services with meals and other senior services in communities through Area Agencies on Aging.
- Increase the maximum amount of care for which frail elderly are entitled, to assure that care is available early mornings, evenings, weekends and holidays, as needed to maintain independence.
- Expand payment rates to providers of services to assure living wages for employees and adequate supply of quality services.
- Increase service delivery options based on successful models that encourage seniors' control over their care, including models already evaluated:
  - ≡ “Cash and counseling” demonstration programs;
  - ≡ Personal care attendants; and
  - ≡ Worker-owned cooperatives.

●"Encourage nursing homes to convert structures and adapt progressive practices to accommodate current needs of frail and disabled populations.

- Assisted living;
- Adult day services;
- Single bed rooms;
- Recreation and rehabilitation care enhancements;
- Independent living accommodations; and
- Pioneer movement, offering residents control over their daily routines.

●Assist nursing home residents who express a desire to leave the home to move to more independent housing.

- Develop programs based on successful models throughout country.
  - ≡ Short-term retention of Social Security payments.
  - ≡ Case coordination assists seniors and family caregivers.
- Encourage development of affordable housing options for seniors throughout state.
- Expand affordable assisted living opportunities.

●Expand comprehensive delivery systems that integrate acute and chronic care and demonstrate cost savings compared to existing fee-for-service models.

- Program for All-Inclusive Care for the Elderly (PACE).
- Social HMOs.
- New integrated delivery system models.

●Develop coordinated information, referral, and entry resources (single point of entry) for all long-term care services available in a community.

- Identify existing models of cost effective information, referral, counseling, and entry to various financing and service delivery options. May include:
  - ≡ Expand role of Case Coordination Unit to cover all long-term care options.
  - ≡ Significantly improve access to and information available from existing telephone hotlines, assuring access during days, evenings, and weekends.
  - ≡ Integrate services available from Area Agencies on Aging with other designated entry points.
  - ≡ Greatly increase efforts to inform families and seniors of resources.
  - ≡ Increase use of automated programs to ascertain benefits and eligibility information.
- Coordinate government eligibility to facilitate application process.

- ≡ Eliminate asset tests for home care where possible to shorten length of application and documentation needed to qualify.
- ≡ Coordinate eligibility guidelines so clients may complete a single application to determine all programs for which they may qualify.

●Pay adequately for care provided by state government.

- Gradually increase nursing home rates to some standard, e.g., Midwest median, comparing like components, targeting additional funds to assure quality and staffing.
- Immediately increase home and community based service rate to achieve living wage and health benefits for their employees.
- Establish programs, as described above, to demonstrate cost-effectiveness of alternative service delivery and financing arrangements.
- Stabilize payments.

●Assure adequate supply of caregivers to meet future increased demand for services.

- Increase wages and benefits.
- Establish career ladder for paraprofessionals from unskilled, to semi-skilled, to skilled professionals.
- Coordinate efforts with community colleges to assure adequate supply of paraprofessional staff.
- Develop incentives for worker-owned cooperative paraprofessional businesses.
- Consider enhancing responsibilities of nurse aides and homemakers through courses equivalent to those taken by higher-level personnel.
- Consider expanding responsibilities of higher-level nurses to maximize human resource efficiency.

●Develop financing scheme to pay for above reforms.

- Utilize funds from nursing home diversions to fund increase of nursing home and home and community based services rates.
  - ≡ Target 15,000 current nursing home residents who report in the MDS to want to leave their home. (20% of \$2 billion = \$400 million at 5% per year from diversion = \$100 million additional funds for home and community care enhancements and expansion for 4 years.)
  - ≡ Plan to assist 3,750 per year for 4 years.
  - ≡ Reduce current placement rates by 10%.

- ≡ Increase collection of fines and penalties for violations and target for quality improvement.
- Identify revenue source to sustain regular rate increases at end of 4-year period.
- Expand use of long-term care insurance.
  - ≡ Educate public about long-term care costs for purpose of encouraging purchase of long-term care insurance for those who can afford it at younger ages.
  - ≡ Explore public/private partnerships to expand affordability of insurance for lower-income populations.
- Establish fund through sale of bonds to finance structural developments and modifications, including:
  - ≡ Nursing homes conversions and remodeling;
  - ≡ Affordable assisted living (SLF);
  - ≡ Adult day services; and
  - ≡ Affordable housing for seniors.
- Decrease rate of placements through moratorium on new bed construction.
- Consider plans to increase federal financial participation.

•Develop administrative structure within state government to assure quality, facilitate coordination, cooperation, and integrated service delivery.

- Eliminate barriers to transfer of funds from institutional to home and community-based service line items during budgeting and appropriation process to reflect changing client demand.
- Establish governor's office task force or deputy responsible for integrating long-term care.
- Enhance role of Ombudsman and other consumer-directed quality control mechanisms.
- Consider integrating aging and long-term care in single state agency or other approaches to assure coordinated services regardless of funding stream.
- Establish locus of long-term care policy expertise.

**AARP**

A comprehensive long-term care delivery system encompasses community and facility-based health and supportive care, including but not limited to in-home services, adult day care, medical transportation, senior centers, nursing homes, and assisted living in individual or small group homes.

The escalating demand for long-term care services has created a crisis in care for which a long-term solution must be found. Seniors will demand increased funding for services that allow them to remain independent longer. State budget problems dictate the need to reduce (or contain) state long-term care expenditures. Families of the frail elderly continue to demand high quality nursing homes for those elderly needing 24-hour care.

The current delivery system presents several pressing problems. Home and community-based care is inadequate to deter unnecessary nursing home placements. Adult day programs are closing due to stagnant reimbursement rates. Sixty counties are not served by such programs. There is a lack of community-based medication management and other home health options. Illinois' service delivery system is fragmented, so that essential services may not be available in every area of the state. All providers face critical workforce pressures in their efforts to recruit, train and retain qualified staff. Over-regulation and inadequate oversight plague both home and community-based and facility-based services. Funding constraints necessitate a rethinking of how and what services should be funded.

- Establish an interagency GOVERNOR'S TASK FORCE ON LONG-TERM CARE AND SUPPORT SERVICES to develop a plan and oversee the development of a comprehensive delivery system.
- Shut down empty Medicaid nursing home beds and reallocate those funds to home and community-based services.
- Establish incentives and opportunities for retro-fitting traditional nursing homes to meet the changing service demands.
- Investigate other states' practices in reducing Medicaid expenditures and preserving the quality of nursing home care. Reimbursement rates alone do not translate into quality care. The state should not assume responsibility for subsidizing a financially failing industry without specifically examining the impact on consumer access to care and gaining a detailed understanding of the actual costs associated with direct care.
- Inspect poor quality nursing homes more frequently. Shut down nursing homes that have both low occupancy and poor quality.
- All funding should follow the client regardless of service setting.
- Integrate acute and long-term care services. Allow clients to manage their own care and in-home workers.
- Initiate nursing home diversion programs, such as those in New Jersey and Colorado.
- Bed taxes or provider assessments should be carefully evaluated. Any such proposal should link rate increases to quality factors, require empty Medicaid beds to be eliminated and dedicate a portion of the fee to fund home and community-based care.

Assisted living oversight is an immediate priority. Budget cuts for fiscal year 2003 eliminated funds necessary to hire investigators and facility inspectors. Failure to fund these positions places the frail elderly at risk and takes the enforcement teeth out of the consumer protections and residents' rights recently enacted.

*Illinois Alliance for Retired Americans:* To improve long-term care focus on 3 goals: 1) better staff-to-patient ratios; 2) better staff training; and 3) better enforcement of the rules and regulations. There also needs to be better communication between long-term care facilities and legislators, and between facilities and the public.

### **THE ALZHEIMER'S ASSOCIATION**

- Provide long-term care services and supports for all who need them, regardless of age, income, or disability.
- Establish a financing system that is progressive, fair for all generations, and protects families from impoverishment.
- Establish eligibility rules that specifically include persons with cognitive impairment who need direct assistance or supervision, reminding or cueing them to perform routine tasks.
- Create a person-centered delivery system that tailors services to the needs of the individual rather than the setting of care.
- Provide appropriate and cost-effective long-term care options, including home and community-based services at home, in adult day care, and in home-like residential care settings, with respite, support and training for family caregivers.
- Create flexible delivery systems that offer consumer choice of providers, including both agency and independent providers, and offer the option for consumers to manage their own services.
- Allow consumer and family involvement in developing individual plans of care, choice of services and providers, and quality assurance.

### **ALZHEIMER'S FAMILY CARE CENTER**

This center is a collaborative effort of Rush Presbyterian St. Luke's Medical Center and the Chicago Veterans Administration Health Care System (West Side Division). The center contracts with the Illinois Department on Aging, the Illinois Department of Human Services Division of Rehabilitation Services, and the U.S. Department of Veterans' Affairs. The center is facing significant financial challenges, because of the difficult obtaining additional donations to cover a funding gap resulting from low state payments and the increasing actual cost of care.

*Sharon A. Adams (Caregiver, Chicago):* There is a need for additional facilities for the care and treatment of Alzheimer's cases.

### **GOLDEN CIRCLE SENIOR CITIZENS COUNCIL**

- More emphasis and resources need to be dedicated to prevention. Funding under the Federal Older Americans Act covers "prevention" service, including congregate meals, nutrition education, information and assistance, outreach, and health screening. These services help by improving personal nutrition; providing information on healthy lifestyle

changes that can improve health; health screenings that can reveal small problems before they become big problems; assistance with information and help with applying for benefits such as the various “Medication Assistance Programs.”

- The “Independent maintenance” program should not be cut. “Independent maintenance” refers to services such as Home Delivered Meals. The need for this program continues to grow. Included in this category is the (Demonstration Congregate Community Care Meals Program) which allows the state of Illinois to purchase meals from (Older Americans Act) Title-III programs for clients who receive homemaker services.
- Other vital services include homemaker services, adult day care, home health care and case management services. They are a very important to the continuum of care needed by many elderly to remain independent.
- A special Demonstration Program has been a great benefit to the elderly of Saline County, the “Congregate Care Demonstration Program”. This is a cooperative effort among the Saline County Housing Authority, Golden Circle, Shawnee Alliance for Seniors, and the Area and State Agency on Aging. It could be replicated across the state.
- Traditional assisted living facilities are also very beneficial. More affordable ones are needed. Other recommendations include:
  - Stabilize adult day care programs. Increase funding for Adult Day Care Programs.
  - Stabilize homemaker services.
  - Service hours a client can receive should be extended.
- The asset eligibility ceiling has not increased since the program began 24 years ago. It is far too restrictive. It needs to be raised.
- Increase the unit rate reimbursement to providers. The reimbursement rate for the homemaker service does not cover the cost of service. To keep a dependable well trained staff, employees need to be provided a decent living wage and benefit. They have to leave for better paying jobs. In the Community Care Homemaker Program there are presently 58 people working, down from over a 100 just a couple of years ago. The turnover rate is 78%. 45 of 58 employees left this year. Supervisory or administrative staff has not been replaced. If service provision is going to be maintained, unit rates are going to have to increase. Community Care staff are caring, dedicated people who deserve to be properly paid for their work.
- Stabilize core Older Americans Act services which support long-term care.
- Rural areas are hurt when it comes to funding formulas. There needs to be a “funding floor” that will help assure that seniors in rural areas of the state have access to services as seniors do in urban areas.

## **CHAMPAIGN COUNTY HEALTH CARE CONSUMERS**

Shift public policy away from providing institutional care and more towards home-based services. Existing home and community-based systems should be expanded in Illinois and new ones should be added.

- Amend the current waiver programs and develop programs that provide home and community-based services to people who are elderly and to people with disabilities. Utilize Medicaid funds to:
  - ≡ Develop programs to support and maintain the independence of people who are elderly and who have disabilities.
  - ≡ Provide in-home support services to families caring for a member who is elderly and/or has a disability.
  - ≡ Expand existing programs and develop new ones to assist people who have been placed needlessly in institutions to a more independent community-based setting.
  - ≡ Stop deeming the income of parents of children with significant disabilities as part of the process to determine eligibility for services for children.
- Develop a consumer-oriented plan to address the future of the long-term care needs of its citizens. This plan should involve policymakers and consumers to examine the state's existing infrastructure for delivering long-term care services and the state's capacity to qualify for new and expanded revenue sources – and manage such revenue effectively over time.
- Continue and expand the new home modification program, to help seniors and people with disabilities to make necessary changes in their private residences to accommodate their needs.

*Jean Wilson (Person with disabilities):* Centers must be able to attract and retain qualified home care providers to people stay. Hospice care and visiting nurses, meals on wheels, physical therapists - these are some of the people and services communities need to have. This is will solve long-term health care problems. Give personal assistants a pay increase.

## **SEIU STATE COUNCIL**

Illinois nursing homes have a large number of problems, many of which are related to short staffing and poor working conditions. As the primary payer for nursing home care, the state bears a large responsibility for these problems because of its historic under-funding of that industry. Cuts in federal funding and the state's budget crisis will cause the crisis to deepen.

In 2002, Illinois nursing homes were cited for 3,168 violations of federal resident care standards. 78% of all homes inspected were found to have violations that caused actual or potential harm to residents, including insufficient staffing; administering unnecessary drugs; unwarranted use of physical restraints; failure to maintain adequate nutrition; failure to adequately treat or prevent pressure sores; failure to treat urinary tract infections; inadequate infection control programs; failure to prevent accidents; and failure to provide necessary services.



- In 2002 Medicaid rates were cut by 5.9%. This should be restored.
- Provider assessments (Medicaid provider taxes) should be restored to previous levels of 6% and the proceeds should be allocated to a Quality Care Improvement Fund to attract more federal matching funds for care.

### **SEIU LOCAL 880**

- The state must begin paying a living wage and providing a health benefit. State payments for homecare workers and homecare agencies allow for a median wage of only \$6.60 per hour – a wage that assures such workers will live in poverty, regardless of how effectively they work. The work must pay better to build and retain a more professional workforce. The state should abandon the practice of creating poverty-level jobs to provide an essential service to some of the state’s most vulnerable populations.
- A task force should be created charged with developing a strategy for providing quality long-term care in the community, provided by workers receiving a living wage and benefits, to the vast majority of seniors and people with disabilities capable of remaining or returning to their own homes.
- Until the state takes steps necessary to lift homecare workers out of poverty, the *de facto* state policy should be regarded as the provision of an inadequate level of basic service to the elderly and people with disabilities, while exploiting a predominantly female and minority workforce.
- The state should recognize the possibility of more than \$100 million in annual savings that could accrue from providing the level of personal assistance that would allow most people with disabilities to leave institutional care and move back into the community.
- The numerous problems affecting the provision of homecare by the state, and denying availability to all who require it, must be addressed systematically. The following steps should be taken by the Governor and the State Legislature:
  - ≡ Immediately raise the wages of all Illinois homecare workers to a living wage – \$9.05/hour.
  - ≡ Provide health care coverage to all homecare workers employed at least 20 hours/week.
  - ≡ Provide for regular cost-of-living increases.
  - ≡ Raise the asset limit for consumers.
  - ≡ Raise the limit on the maximum number of hours of care for which a senior can qualify.
  - ≡ Create a commission to conduct a study that will establish the true cost of long-term care in the community and in institutions to guide choices within the state budget.
  - ≡ Create a state task force to develop a strategy for delivering quality long-term care to individual consumers in an environment appropriate to their needs.

Carolyn Rivera, CNA: Hire additional staff. Increase wages.

Shirley Kellom and Kitrell A. Lucas (Chicago): Homecare workers need more pay to ensure there is enough qualified staff.

### **ILLINOIS COUNCIL ON LONG-TERM CARE**

Nursing homes in Illinois need to provide better service. The nursing home profession is beset with many problems: poor image; media exposes; insufficient staff; inadequate funding; an enforcement system nobody likes; and lack of customer satisfaction. There has to be a better way to provide health care services in Illinois. The current long-term care system needs to change.

The state's public policy should be to integrate the disparate home and community-based services into a well-managed continuum of care, from home-care all the way to sub-acute care and rehabilitation services. Nursing homes should evolve from hospital-looking environments to more home-like settings that offer specialty services and private rooms. Resident-centered care should be the underlying theme of care in the future, with incentive grants offered to facilities that develop new and innovative practices. The state can help consumers by publishing the kind of services, specialties and satisfaction levels for each Illinois nursing home on the Internet. In addition, the state enforcement system should help consumers find good facilities by focusing on care outcomes, rather than hundreds of minor technical mistakes that have no real impact on resident well-being.

The state should maintain its commitment to enabling elderly citizens to live at home and receive community-based health care whenever possible. Nursing homes should strengthen their focus in providing higher-level skilled nursing and rehab services in the state's continuum of health care.

In each local area, there should be a single source referral center that coordinates the most appropriate, cost-effective placement within the continuum of home and community-based services.

Progressive public policy should decrease the competition between home-based services and nursing homes for clients and more effectively assess the services clients need and where they need it.

The transition between home care and day care, and home health and assisted living, and nursing and rehabilitation centers should be more smoothly integrated and case managed, so clients receive the most cost effective care in the least restrictive setting.

To improve living environments in the future, nursing homes should be smaller, with residents living in private rooms whenever possible. These environments need to be more "home-like" and stimulating in nature, filled with plants, animals, and children for emotional health; fitness areas for physical health; safe outside parks for persons with dementia; and internet areas and entertainment sections for mental stimulation and family communication. In addition, these facilities should provide ample transportation opportunities so that the residents can spend more enjoyable hours in the community.

Additionally, it is far more cost effective to revitalize existing nursing homes than construct new ones from scratch. Effective financing and bonding approaches can aid existing facilities to upgrade for modern technology, resident centered equipment, and solar panels and other heating efficiencies.

Nursing homes promote resident-centered care, meeting the specific needs of each individual resident. This theme is the hallmark of the Pioneer Movement: designing programs to give residents more day-to-day choices in their life routines, and empower front-line staff to make more care decisions for the residents they serve. Across the nation, nursing home providers are looking beyond the traditional nursing home model to develop new and innovative ways to meet each resident's individual care needs. The kind of management and staffing changes these programs require, however, are often beyond the means of Medicaid nursing homes. The state should sponsor an incentive program for those progressive Medicaid facilities willing to invest in innovative, non-traditional approaches to care.

Besides promoting innovation, the state can better meet residents' specific health care needs by certifying nursing facilities based on their specialties. Categories for certification include Alzheimer's disease, stroke, cardiac care, diabetes, skin care and many others. These certifications would help consumers make better nursing home choices, selecting nursing facilities that have the most expertise in the treatment of specific medical conditions.

The state could also help consumers make sound health care decisions by developing resident and family customer satisfaction surveys, sharing these results with the public through the Internet or by publishing an IDPH consumer guide on choosing a nursing home. These materials should emphasize 3 key areas: the restorative and rehabilitation services that each nursing home provides; the medical specialties of each facility; and the customer satisfaction levels of the individuals served by each home.

This emphasis on care delivery and outcomes should carry over to the state's survey enforcement system as well. The state should focus its system on the results of the care residents receive, with less emphasis on the hundreds of current survey items that have no impact on resident well-being.

3 key areas for change:

- Create quality staff for quality care.
- Develop smaller and more specialized facilities in a continuum of community based care.
- Refocus on resident-centered care within the context of cost accountability.

Related recommendations for short and long-term changes:

- The Illinois nursing home system should be dramatically transformed and strengthened.
- A 5.9% rate cut last year, no increases this year, skyrocketing staff and liability costs, and erratic and unpredictable payments from the state have all created a crisis atmosphere where some facilities will not survive. Illinois needs to stabilize Medicaid payments and restore the 5.9% Medicaid rate cut made in July 2002, with future Medicaid reimbursement reflective of the continuing cost of caring for an increasingly fragile population.

- The most effective way of raising needed funds is through a provider tax, which brings in increased federal matching funds without any cost to the state general revenue funds. This would prevent a severe disruption to the continuum of the healthcare delivery system, help address some of the geographic discrepancies in nursing home rates around the state, and lay a foundation in long-term changes for the future.
- To stabilize payments for providers, at no cost to the state, a Medicaid receivable bond program should be authorized through the Illinois Development Finance Authority. This would give providers a regular payment cycle, and provide some up-front cash so providers can pay the provider tax. The cost of the bond financing program is borne by the providers, although at an interest rate below commercial markets.
- To improve nursing home care in the future, state government must be partners with the nursing home profession to encourage more and better paid and better trained staff.

Specific recommendations include:

♦Career Ladder Programs — Implement the law passed 2 years ago that required the Illinois Department of Public Health to develop a nurse assistant career ladder program. This program would provide opportunities for nurse aides to receive advanced training, provide better resident care, and enable them to reach higher levels in their professions with increased pay and status. In addition, their training can be used as a bridge towards helping them become nurses. Working with the universities, unions and providers, the state can establish the standards for advanced training. Once standards are agreed upon, the schools, unions and providers can work together to implement the career training that will open up doors of opportunity. Some of the provider tax money can be used to establish the training programs in pilot sites around the state.

♦Medication Technicians — Develop a state medication technician program. Through this program, nurse aides receive up to 100 hours of both classroom and clinical training on administering medications. Working under the direct supervision of a licensed nurse, the medication aides would be able to pass out routine medications to residents. This program would not reduce the number of nurses in nursing homes, but free up nurses for more direct bedside treatment. Currently, at least 13 states successfully use medication technicians in nursing homes, including Indiana, Iowa and Wisconsin.

♦Nursing Scholarships — The state should dedicate 20% of its existing nursing scholarship programs for nurses who are willing to work in long-term care. The state pays for these scholarships out of existing license fees and fines.

♦Single source case management referral system — There should be a consistent, impartial area case management referral agency – without any ties to a particular provider agency – to assess an individual's needs and serve as a resource to clients and families to assemble the best array of services in the community to meet a client's needs.

♦A Moratorium on the Number of Nursing Home Beds — With the appropriate increase in home and community alternatives to nursing homes, there are nearly 15,000 unused nursing home beds in Illinois. Excess beds equal inefficiency; more beds than people drive up costs, and creates insecurity in the healthcare delivery system. Too many nursing home beds in the system cause unnecessary competition for clients with home and community-based services. Those empty bedrooms are a waste of health care resources and could be converted to

modern, quality living space for residents. There should be a freeze on the number of new nursing home beds in Illinois. The health facility planning process could issue a moratorium on nursing home beds.

♦Create a Bond Program for Downsizing Facilities — To reduce beds, support a bond program for nursing home modernization, and establish an equity capital rate for those homes converting unused beds to quality living space and private bedrooms. Similar "buy back" or conversion programs exist in Minnesota, Iowa, Nebraska, Ohio, and Wisconsin.

♦Modernization — Low-interest renovation loans through the Health Finance Authority can help transform last century's infrastructure into modern, efficient, people-friendly living environments.

♦Quality of Care Commission Providing Incentive and Innovation Grants — Develop a Quality of Care Commission to review grant applications and provide incentive payments to nursing homes that develop new and innovative practices. Incentive payments would be tied to specific program improvement and deliverables that increase residents' quality of life and empower front-line care-giving staff.

♦Certification Programs for Specialty Care — Develop certification programs for specialty areas of care.

♦Statewide Resident and Family Satisfaction Surveys — IDPH should work with the provider associations, universities and consumer research experts to develop resident and family satisfaction surveys. Other states, including Michigan, have successfully developed this type of program. Share the results from these surveys with consumers, in order to help them make sound decisions on the choice of a health care setting.

♦IDPH Consumer Guide Website Based on Services, Specialties and Satisfaction — IDPH should develop a consumer guide website that reports the restorative services, medical specialties and satisfaction levels for each nursing home in Illinois. This information could also be printed and made available to consumers in a book format.

♦Enforcement Program Based on Sentinel Resident-Centered Events — A more progressive enforcement system should emphasize actual resident care outcomes, rather than the thousands of minor technical mistakes that can happen in every health care setting. The federal government's 30 "sentinel care" outcomes – based on extensive computerized resident assessment data - provide an effective springboard for evaluating the overall quality of care provided in each Illinois nursing home, allowing enforcement agencies to target areas that warrant more intensive investigation, without bogging themselves and the nursing home community down in investigations that do not effect resident care.

Nursing home care should be integrated with community care. The state's priority should be to strengthen independent living so people can live in their own homes as long as possible. Nursing homes should provide more home-like settings whenever possible. The (Medicaid Provider) assessment should be increased, so the state could receive \$100 million in additional federal funds. A moratorium should be placed on new nursing home beds, in addition to affecting the closure of unnecessary beds or converting them to assisted living. 20% of nursing scholarships should be reserved for candidates who commit to long-term care service.

### **LIBERTY VILLAGE OF MARION**

The present proposal to reimburse facilities from the MDS assessment tool will not work without adequate funding.

With insufficient funds to provide an adequate wage, long-term care facilities are unattractive alternatives for nursing professionals and other caregivers who can pursue higher paying jobs.

Give attention to attracting qualified caregivers into the honorable profession of long-term care with adequate funding and careful regulation.

### **ILLINOIS CITIZENS FOR BETTER CARE (WENDY MELTZER)**

Illinois should be making it possible for people who want to stay home to do so, when staying home would cost no more than nursing home care.

This is a partial list of how to do this:

- Revise the formula used to determine for how many hours of home care the state will pay for people over 65, so it is an honest comparison of home care vs. nursing home care for each individual.
- Instead of capping the hours at the theoretical maximum, Illinois should be exploring creative use of the Medicaid waiver to help families who are caring for their relatives: for example, the state would pay for one hour of care over 6, for each hour the family paid for or did themselves, up to some maximum.
- Expand the availability of adult day care, especially for people who are incontinent. Expand the availability of accessible transportation to and from adult day care. This can be done not by buying a lot of new accessible vans, but by facilitating dual use of existing accessible vans owned by, for example, day training programs and nursing homes.
- Illinois should expand the number and breadth of its existing home-sharing programs, both for full-time residences and for day-time only care, so elderly adults can be cared for while their family members are working. Tie home-sharing into the Assistive Technology project, and existing Medicare funding for occupational therapists, who can do home visits, assess individuals, and make recommendations about what equipment and home adaptations can allow disabled elderly people to stay home safely.
- Create a central clearinghouse of available services, especially housing with supportive services and personal care services.
- Put supportive services into existing senior housing, such as CHA senior buildings.
- Make the services available under the Medicaid waiver programs, uniform for all groups.
- Work with high schools that require community service credit for graduation, to refer students to programs that do shopping and home-delivered meals for home-bound people.

- Make doing home care, and working in equivalent programs — day training, adult day care — more attractive by providing health insurance to the people who do this work.
- Stop using nursing homes as housing of last resort, sticking people in them because there is no place else to go.

These are some of the things what needs to be done:

- As a general rule, Illinois should require a minimum percentage occupancy to participate in the Medicaid program. There have to be exceptions to this in rural areas, where closing a nursing home would mean that families would have to travel unreasonable distances to visit their relatives. When exceptions are made, the priority should be on funding the county homes and the not-for-profits, at least those not-for-profits that agree to admit residents on Medicaid.
- Increase the number of Public Health nursing home surveyors. So many have taken early retirement, the department has lost its ability to do thorough complaint investigations, or initiate surveys of facilities that have repeated serious violations.
- Expand the IDPH legal staff, so that the department does not feel pressured to settle cases because it does not have the staff to try them.
- Inform families and guardians of residents when a violation occurs in a nursing home that affects them.
- Teach families of residents how to help their relatives when they move into a nursing home, including what nursing homes' obligations are to their residents. Tie this into the universal prescreening.
- Since Medicaid reimbursement is going to be based on the "MDS," we need to be checking on the accuracy of the information nursing homes enter in the "MDS." "MDS" refers to the new Minimum Data Set methodology that has been recently promulgated by the Department of Public Aid that will be used to determine payments to nursing homes for the cost of patient care.
- Future Medicaid rate increases should be "targeted" — that is, their use restricted — to salary for direct care staff and food.
- While in some ways the IDPH website is helpful, the majority of nursing home violations are not posted, despite the legal mandate that they be there. IDPH should either do the work itself, or contract with an entity able to do the job.
- Strengthen the ombudsman program.
- While having the ombudsmen function as friendly visitors is inappropriate, it would improve residents' lives if high school mandatory service programs expanded to include having students assigned to specific residents and visit them regularly.
- The Office of State Guardian needs both the resources to spend enough time on all its wards, and the mandate to function with the same vigor as would any private guardian concerned with a ward's welfare.

- Increase the personal needs allowance. If the personal needs allowance had kept pace with inflation, it would be over \$90/month.
- Care in nursing homes will improve only when the people working in them feel personally obligated to do a good job. The CNA abuse/neglect registry is at least an attempt to hold CANs liable for poor care. There is nothing comparable for people higher up on the food chain. The Department of Professional Regulation does not even open files on the large majority of referrals the Department of Public Health makes to it, of medical professionals and nursing home administrators who appear to have violated their responsibilities under the Nursing Home Care Act. Public Health does not bother to make referrals of mandatory abuse/neglect reporters who ignore their legal obligations.

Public Health and the Attorney General should be training state's attorneys, sheriffs, and local police departments on criminal laws relevant to protecting nursing home residents, including the accountability provisions of the Criminal Code, and mandatory reporting requirements. Public Health should be working with the Hospital Association to train and retrain hospital employees (especially emergency room personnel) on mandatory abuse/neglect reporting laws.

### **PROVENA PINE VIEW CARE CENTER**

It is increasingly difficult to generate a reasonable income while providing quality care, due primarily to the poor reimbursement given in this state for residents on Public Aid. Direct costs for providing care at Provena runs almost \$140/day, but the state pays only \$92.50. Traditionally, Medicare and private pay residents have helped to offset this difference, but the recent cuts in Medicare and the declining number of private paying residents makes these options less viable. Without additional state funds, nursing homes cannot pay for the staff necessary to provide quality care. Essential services must be funded first. Care of the frail elderly should be an essential funding priority for the legislature.

- Restore the 5.9% cut in Medicaid funding for nursing homes.
- Stop initiatives that tax providers who are already burdened with financial problems.
- Encourage the purchase of long-term care insurance.
- Explore Medicaid disproportionate share programs in regions with high poverty rates.
- Explore incentives for facilities to diversity their funding.
- Support quality care of the frail elderly in various settings.
- Work cooperatively with all of the long-term care organizations to provide a quality system of care for the frail elderly of Illinois.

### **RDK MANAGEMENT – HERRIN PROFESSIONAL CENTER**

The MDS or Minimum Data Set, which is currently used by all Illinois nursing homes to assess resident condition, is a very important tool which can be utilized to develop Medicaid rates based on actual resident needs and abilities rather than by the arbitrary and subjective methods previously used. As of July 1, 2003, facilities are submitting the MDS information electronically on a quarterly basis. There must be funding in order to have a total transition to this new system. Continue to meet the needs of our southern Illinois seniors. Make sure the MDS system of funding is implemented. Work with the healthcare profession to find the dollars to fund the transition to the new system.

Staff deserves to be rewarded for the work they perform.



## **ILLINOIS HEALTH CARE ASSOCIATION**

The legislature should not plan services only on the basis of available appropriations, but a combination of individual needs and state resources. Do not commit to providing a service if the economic and human resources are not available to provide a quality service.

Prepare as much as possible for a seamless network of services that recognizes needs from primary care to acute and sub-acute care.

IDPH should implement legislation passed a year ago that would allow use of up to 50% of civil monetary penalties paid in fines by nursing homes for demonstration projects to improve quality-of-life in nursing homes that then can be exported to nursing homes throughout the state.

Continue progress in the use of an MDS-based system to measure acuity levels coupled with cost reports from nursing facilities to adequately fund the system.

Commit up-front to reimburse for new services on the basis of patient diagnosis and needs coupled with what it would reasonably cost to provide the services.

Work with health professionals to develop critical pathways to move people back and forth throughout the system as the health care needs change.

Develop an effective case management system focused on both adequacy of service as well as the cost-effectiveness of the setting in which the service is delivered.

## **LIFE SERVICES NETWORK**

Recognize that a priority of government is to help citizens who cannot help themselves.

- Restore Medicaid funding that was taken away last year.
- Change the state's budgeting priorities.
- Don't expand the provider tax.
- Explore incentives for facilities to diversify their funding mix – Medicaid, Medicare and private pay and generate public support.
- Explore a nursing home Medicaid disproportionate share program in regions with high poverty rates and unemployment.
- Encourage the purchase of long-term care insurance.
- Support the enactment of the current Nursing Assistant Career Ladder Law and provide funding for the salary increases tied to the advanced status.
- Use CMP (civil monetary penalties) for education programs to encourage the development of frontline staff in their clinical skills and help staff to learn about and implement culture change practices.

- Increase Medicare and Medicaid reimbursement and funding mechanisms to fully cover long-term care labor costs to improve wages of direct-care workers and thereby greatly enhance recruitment and retention efforts.
- Develop more attractive benefit packages, utilizing tax incentives or Medicaid “buy-in” for health insurance coverage, and addressing other needs in transportation, meals, housing and child care in order to attract and keep frontline workers.
- Support a strong and effective state regulatory system designed to foster accountability at the highest standards of care. Concentrate on the desired service outcomes and resident satisfaction.
- Stand firm in the approach to regulating assisted living so that it provides and protects resident choice.
- Develop a more collaborative approach to nursing facility surveys; one that allows surveyors and care-giving staff to work on promoting and achieving sustained compliance, and meeting individual care needs and expectations to improve care.
- Create a new system, one focused on outcomes and continuous quality improvement, rather than process. The focus of the survey and enforcement process should be on fixing problems and offering expert guidance rather than on punishment.
- Urge Congress to approve the following proposals:
  - ≡ Eliminate the arbitrary 2-year disqualification from nurse-aide training for noncompliant facilities, allowing facilities to resume their nurse-aide training programs once deficiencies are corrected and compliance is demonstrated.
  - ≡ Authorize waivers for demonstration projects in up to eight states to develop and explore innovative approaches to measuring quality of care.
  - ≡ Give states flexibility in terminating facilities from the Medicare and/or Medicaid programs, which is currently required at 180 days based on any level of noncompliance.
  - ≡ Provide a truly independent informal dispute resolution process for facilities to challenge severity and scope determinations.
  - ≡ Enforce the mandate that states use Civil Monetary Penalty funds to improve resident care, and expand the permissible uses of these funds.
  - ≡ Allow citations to be appealed even if no penalty is imposed.
- Permit surveyors to share information on best practices during the survey process.
- Closely examine what possibilities and options can be made available to provide affordable housing and assisted living to the residents of Illinois to try to meet existing and growing needs. Innovative funding resources (incentives for public or private partnerships, etc.) need to be considered as federal funds continue to evaporate.

- The Supportive Living Program needs to be expanded. This cannot be done until the moratorium is lifted.
- A cooperative effort between the agencies responsible for housing (residential settings) and services for our elderly must take place to meet the needs of this population. One example of this would be to examine the coordinated use of Community Care Program services in HUD subsidized settings where an aging population lives. A close look at those settings that were a part of the Community Based Residential Facilities demonstration program might shed some light into other alternatives.
- Urge Congressional approval of more equitable treatment for Illinois in the Federal Medicaid Assistance Program.

### **PEACE MEMORIAL MANOR**

- Safe affordable housing allows seniors to live independently with some assistance if needed. More funding should be directed to facilities that meet these needs.
- Explore more federal funding through the U.S. Department of HUD to fund assisted living facilities.

### **PERSHING NURSING HOME**

- Nurses' salaries or wages should be raised so the nursing home industry can attract and retain qualified staff.

### **4 FOUNTAINS**

- Need more funding for nursing homes;
- Need to increase wages to attract and retain qualified staff;
- Need to make sure money is well spent in facilities; and
- Provider tax continues to be a problem.

*Jim Snyder (Director, Carle Arbours):* Nursing homes are shifting costs to their private pay residents. Incentives, including financial aid for scholarships, should be provided to recruit quality long-term care staff.

*Steve Krohl (Alden Group):* There are 4 main challenges for nursing homes: 1) staffing; 2) medical malpractice; 3) theft; and 4) government reimbursement. Caps must be put in place on punitive damages awarded in malpractice lawsuits. The theft of seniors' assets by family members must be reduced dramatically. The state must pay nursing homes and other senior health care providers promptly to ensure that they will not be driven out of business.

*Dave Sower (Heartland Manor, Casey, Illinois):* Heartland Manor costs are \$103/day, but state reimbursements are only \$84/day. Fifty percent of the residents are covered by Medicaid, so the shortfall in state payments must be covered by private pay rates. The cost of insurance has skyrocketed.

### **SOUTHWESTERN ILLINOIS VISITING NURSE ASSOCIATION (SIVNA)**

Classify self-neglect as elder abuse, as other states do, so that more resources could be drawn upon in efforts to assist the client.

Increase funding for home modification equipment (i.e., safety ramps, grip-bars) so that seniors can remain safely in their homes.

Increase the availability of affordable, adapted housing for seniors, including temporary, emergency housing when existing homes are condemned. There is a need for additional supportive and assisted living facilities as alternatives to nursing home placement.

Emergency response systems should be placed in client homes to signal when a person falls or is injured. The cost should be underwritten by a capped contract with the State of Illinois.

Provide additional hearing aid assistance for low income persons, including aid in identifying resources and completing applications for assistance.

Provide additional dental care to area residents.

Provide more transportation for clients requiring medical appointments, including the 2-to-3 visits per week required for dialysis. This is an especially acute need in southwestern Illinois.

### **NCB DEVELOPMENT CORPORATION**

Focus attention on a very effective state program in Illinois – called the Supportive Living Program – that makes assisted living affordable to seniors of every income range. It was designed by the Department of Public Aid to provide a residential alternative to nursing home care for low and moderate income seniors who are too frail to live alone, but who do not need ongoing skilled nursing care.

Urge the state to lift the current moratorium on accepting new applications to the Supportive Living Program, and aggressively expand it to reach those frail, low-income seniors who are most in need. The state can accomplish this by working with those sponsors who currently provide affordable housing to low income seniors.

Work to promote the development of these facilities in locations where there are the largest concentrations of low income seniors: in rural areas and in low income urban neighborhoods.

There must be a sense of urgency to this evaluation and consideration, resulting in a comprehensive plan to promote deinstitutionalization and to find alternative uses for underutilized nursing homes.

The state must give careful consideration to a rational deinstitutionalization initiative such as that implemented by Iowa and Nebraska.

### **HEARTLAND HUMAN SERVICES**

Continue/increase respite for family caregivers. Provide respite care to be an option in the early to middle stages of care giving, not just the late stage. Keeping older persons in their own

homes is important. In-home care services must be flexible and accessible for family members who are caring for a senior in their home. Respite hours need to be available to family caregivers more than a usual 8-4 or 9-5 work day. Having flexible service with options that meet the needs of families will assist them in continuing to care for their aging family members.

### **FRIENDS HOME CARE, INC.**

There are many seniors who do not meet the needs based requirements of the Community Care Program or Medicaid, but still need some help to stay at home. More importantly they wish to remain at home instead of going to live in an institution of one type or another. Agencies that service seniors who will be paying for their own care do need to provide high quality, in home care for seniors.

### **CIRCLE OF FRIENDS ADULT DAY CARE CENTER**

Illinois citizens need and want adult day services, and the State of Illinois needs service providers who make efficient use of state resources.

### **ILLINOIS ADULT DAY SERVICES ASSOCIATION (IADSA)**

Stop the Closing of Adult Day Crisis Centers in Eldercare. Twenty-one programs have closed in the last 3 years. The true cost of care is \$8.32 per hour, current reimbursement is \$6.02. In Illinois only 82% of adult day center's cash expenses are covered by net operating revenue.

Illinois' adult day centers need adequate funding to continue providing services to frail seniors. Support re-allocation of \$930,000 within the IDOA budget earmarked for ADS expansion to provide a \$.50 rate increase for current providers.

### **NWCH ADULT DAY CENTER**

In Illinois over half of the counties lack adult day services and many do not operate with extended hours. Increase the availability of adult day services both in location and in hours available. In order to do this adult day centers should be provided with adequate funding to meet the service needs of the population.

There are 3 issues in Illinois that impact availability:

- The Office of Rehabilitation Services rate has not kept pace with the Illinois Department on Aging rate.
- The Illinois Department on Aging's transportation rate does not cover the actual cost of transportation for adult day centers. Transportation is a crucial part of a center's viability.
- Provide equity in the Illinois Department on Aging's hourly reimbursement rate. Currently, Illinois adult day centers net operating revenue only covers 82% of their cash expenses. This has resulted in multiple closings across the state and does not make adult day services an attractive business for new providers.

## **CITIZENS FOR HOMES (HOUSING OPTIONS MEETING EQUITY STANDARDS)**

Consumers want more control over their long-term care services. They want to be able to direct their own care and hire their own caregivers whenever possible. They want to remain in their communities and participate in community life. A key component to an effective long-term health care plan must include an increase in accessible housing.

Georgia and Texas have passed laws that require new homes built with public funds to contain basic access features, including:

- 1 zero-step entrance;
- 32 inch wide doors on the ground floor, including the bathroom;
- Reinforced bathroom walls so grab bars may be installed if needed; and
- Light switches, electric outlets and other controls at reachable heights.

The additional cost of these homes ranges for \$0 to \$500.

Considering the present and future need for an increase in accessible housing, Illinois should require new homes built with public money to contain these design features.

## **PROVENA COVENANT CASE MANAGEMENT UNIT**

Provide comprehensive case management services to all seniors, regardless of income and assets. By allocating state grants or contract assistance to Case Coordination Units (aka: Case Management Units) via Area Agencies on Aging, comprehensive case management services can be offered to all seniors, regardless of their eligibility for Community Care Program services.

The initial, annual respite care assessment that may be authorized per person stands at \$500 – with the option to request an addendum up to \$250 on a case-by-case basis. This \$500 maximum provides about 5 days/nights of Institutional respite (in a nursing facility), 38 hours of homemaker assistance, or 11 days at an Adult Day Service site, per fiscal year. The respite care allowance per person should be increased from \$500 to at least \$750. Appropriate the necessary state funds to provide emergency home response services under the current Medicaid waiver to seniors eligible to receive Community Care Program services.

Under the Community Care Program (CCP), individual seniors must have \$10,000 of assets or less. The current asset limit of \$10,000 for a single person should be raised to \$20,000 under the Community Care Program (CCP).

CCP rates for homemaker services should be increased so that providers may offer fair wages and benefits and seniors may have a better chance of receiving service hours as authorized.

Provide mileage reimbursement for the volunteers who participate in the Illinois Volunteer Money Management Program (IVMMP).

Seniors across the board should have access to money management services and that the funding is appropriated to allow for this to happen.

## **STATE FARM INSURANCE**

100% of LTC costs should be eligible for a federal income tax deduction. Some states already allow some deductions.

## **SENIOR COMPANION SERVICES**

Seniors need more adult companions.

## **AREA AGENCY ON AGING OF SOUTHWESTERN ILLINOIS**

The main concern is mobility – being able to get from one place to another. A consumer-responsive transportation system throughout the 7 Southern Illinois counties is a key to maintaining individuals in their home and community.

The senior service system must increase the awareness of how to maintain individual health. Medications must be affordable. Maintenance of affordable housing is a priority.

The system must be a continuum, from educating the young about healthy aging to providing quality care in nursing homes. The system must be seamless, with easy access. Choice of services, providers and locations must be available, including senior companions, assisted transportation, and adult day services.

Illinois should integrate federal and state funding sources for home and community-based services in order to raise monthly maximums for older persons under the Community Care Program and offer seniors a wider array of service options.

Funds should be appropriated for additional services provided under the current Medicaid waiver, including home-delivered meals, transportation and personal electronic response systems. Illinois should amend the current Medicaid waiver to include “targeted” case management on clients with special needs, including persons with dementia, complex chronic illnesses and disabilities, and clients who are capable of leaving a long-term care facility and returning to the community with appropriate home and community-based services. Targeted case management could generate additional federal participation.

Illinois should appropriate state funds for respite services to provide temporary and intermittent relief and assistance to individuals providing constant care to older adults in the community.

Improve and expand the Long-Term Care Insurance Partnership Program to provide incentives for individuals to purchase private long-term care insurance and protect their assets if they need to apply for Medicaid in the future to cover the cost of long-term care.

## **SUBURBAN AREA AGENCY ON AGING**

The state needs to direct more resources in support of home and community-based options. Illinois needs to do a more effective job of integrating federal, state and local resources in support of home and community-based services. The following steps should be taken to improve the long-term care system in Illinois:

- Increase state funding to Area Agencies on Aging for assistance to local programs on aging to provide home and community-based services including: transportation, home delivered meals, medication management, and money management.
- Raise the asset limit for eligibility for the Community Care Program (CCP) from \$10,000 to \$20,000. The current asset limit has not been increased for the last 20 years.
- Integrate federal and state funding sources for home and community-based services to raise monthly service options in response to their needs, especially home health services.
- Appropriate state funds necessary to provide all service options authorized under the current Medicaid waiver to seniors eligible for the Community Care Program across Illinois, including home delivered meals; transportation and personal electronic response systems.
- Amend the current Medicaid waiver to include “targeted” case management to help older persons manage chronic illnesses and disabilities at home and help older persons who have the capacity to leave a long-term care facility and return to the community with appropriate support services. Targeted case management may also generate additional federal funding.
- Allocate state grants or contract assistance to Case Coordination Units through the Area Agencies on Aging to provide comprehensive, holistic case management services.
- Increase the CCP rate for adult day care services to \$8.32 per hour to meet current actual operating costs and prevent the closure of more adult day care centers across the state.
- Increase the CCP rate for homemaker services to provide fair wages and benefits to workers and prevent the impoverishment of workers who provide long-term care.
- Build career ladders for homemakers by providing opportunities for continuing education to build their capacity to respond to the changing needs of their clients.
- Conduct a “Cash & Counseling” demonstration project in Illinois, comparable to projects in Florida, New Jersey and Arkansas, to determine the feasibility of offering older adults the option of hiring and directing their own personal care attendants.
- Enact the Family Caregiver Act (House Bill 1196 and Senate Bill 1620) and appropriate state funds to the Illinois Department on Aging through Area Agencies on Aging to provide family caregiver support services including respite care.
- Improve and expand the Long-Term Care Insurance Partnership program to provide incentives for individuals to purchase private long-term care insurance and protect their assets if they need to apply for Medicaid to cover the cost of long-term care in the future.
- Provide deductions to taxpayers for the purchase of long-term care insurance to provide economic incentives to citizens to plan for future long-term care expenses.
- Develop affordable assisted living options such as supportive living facilities and provide state funds necessary to provide supportive services for eligible older persons.



- Seek expansion of the Medicaid waiver to include prescription drug assistance coverage for older persons with incomes within 250% of the federal poverty.
- Oppose the imposition of federal funding caps on Medicaid 1,115 waivers, which would limit federal financial participation in support of home and community-based services.

### **EGYPTIAN AREA AGENCY ON AGING**

The demonstration program, operated by the River to River Residential Corporation, is different from the Supportive Living Facilities or SLF model which is administered through the Department of Public Aid. This model for assisted living in southern Illinois demonstrates how middle class senior adults can afford assisted living while maintaining their savings and retirement income. The model combines affordable rent for the facilities' apartments with state supported services through the Department on Aging's Community Care Program (or CCP) provided in these facilities. Unfortunately, the model may not be continued without legislative support to reauthorize the Department on Aging to continue its assisted living demonstration program under the CCP program. The legislature needs to reauthorize the Department on Aging's assisted living demonstration under the CCP program.

In May there were 102 CCP-eligible tenants living in our affordable assisted living facilities. Of these 102 tenants, nearly half (45 tenants) would have to spend down their assets to qualify under the SLF model, including 34 tenants who would spend down more than \$1,000 of their assets. Seven tenants would end up with less money per month under the SLF model than they keep now. The SLF model allows tenants to keep only \$90 per month of their income. The costs for housing and services for these 7 individuals under the model allow them to keep more of their money each month. 2 of the tenants in this group would also have to spend down their assets giving them a "double penalty" if they participated under the SLF program. Potentially, there are as many as 53 tenants out of a total of 102 CCP-eligible tenants who would be negatively affected financially if this model for assisted living is abandoned for the SLF model. The only way that middle class seniors can participate in assisted living is under the SLF model which means that they will be forced to impoverish themselves first to become eligible for the SLF model.

Elimination of the co-payment system for home support services would greatly serve the senior population and would also provide a cost incentive for all those agencies.

The asset level should be evaluated and increased.

Mandatory Medicaid participation of clients requires further attention and analysis.

Home care services need to be more flexible and accessible. Service options need to be expanded. There is a great need for funds to be available for home modification and assistive technology. Programs which have demonstrated success in limited areas should be expanded statewide.

### **MIDLAND AREA AGENCY ON AGING**

Make home and community based services the preeminent means of meeting the needs of older persons and their families in maintaining older persons in their homes.

The maximum asset level for eligibility should be raised from its present \$10,000 where it has been since the program's inception in 1980 to \$20,000.

Amounts required for co-payment for services should be reevaluated and reduced as the budget constraints permit.

The Medicaid waiver to include other allowable services such as home health, targeted case management, personal emergency response systems, and home delivered meals, which are currently allowable under waivers.

Revive adult day center services throughout the state with reimbursement rates equal with the cost of providing service.

Heed the request of the adult day care association and other aging organizations to increase the reimbursement rate. Provide incentives for new day care development.

Provide targeted case management services to recipients under Medicaid.

A portion of the \$1.5 million in Illinois GRF funding currently being allocated to case coordination units by the area agencies for case management could be used to leverage additional federal financial funds under Medicaid.

Expand the Medicaid waiver to include reimbursement for home delivered meals to Medicaid eligible clients.

Expand the Medicaid waiver to include reimbursement for home health services specifically, medication management.

Nursing homes should be provided with incentives to convert portions of existing facilities to accommodate alternative living styles including short term stays for respite care, adult day care services, and assisted living units.

Although we have transportation systems funded under Section 1511 of the federal Transportation Act, and administered through the Illinois Department of Transportation, glaring voids exist in transportation availability. A senior who lives in one county and must travel to another to obtain kidney dialysis or chemotherapy has no transportation available to them. In 2 other counties, Medicaid reimbursed medical transportation is not provided by the Mass Transit District.

There is also a lack of transportation in 2 counties for persons who reside outside city limits, or to whose small towns no scheduled transportation routes are available.

The state should develop a comprehensive rural transportation system. The Illinois Department of Transportation should develop guidelines and standards for rural transportation systems which provide an expectation that at a minimum require transportation to and from sources of medical care necessary for life threatening illnesses and condition. The state should also arrange for regular monitoring and assessment of transportation providers to assure that effective use of existing contract funds is being accomplished.

The community Senior Services and Resource Center Advisory Committee created under House Bill 2413 should allow small rural senior centers access to the funds authorized by that new law to enable them to staff their centers. There is also a need for renovation and relocation assistance for aging centers some of which are over 100 years old.

Develop a mental health system which is responsive to mental health needs of older adults. In southern Illinois, through a collaborative effort of the southern network of mental health and 3 area agencies on aging, a demonstration project has been in progress for 3 years. The mental health and aging systems integration, or commonly called MHSA, has been showcased statewide as a model project for adaptation or replication. Partial project funding has come from the Office of Mental Health. Support and expand this mental health and aging initiative.

█ *Kathleen Allison (Area Agency on Aging):* There is a serious problem with financial exploitation of nursing home residents by their families.

### **ILLINOIS STATE LONG-TERM CARE OMBUDSMAN (SALLY PETRONE)**

Recommend that nursing home corporations and facilities make an honest effort to transform the culture of elder care in licensed long-term care facilities from a medical model to a social model thereby using Pioneer or culture change practices. The heart of the Pioneer movement is about transforming facilities into humane, caring, and nurturing environments in which frail elders and other people with disabilities can thrive.

Request IDPH to release monies collected as civil money penalties and use them to benefit facility residents. These funds are collected from nursing homes that have been out of compliance with federal requirements. These funds should go toward an increase in ombudsman services, to develop education materials distributed to deficient nursing homes, and to fund culture change projects such as Pioneer practices and the Eden Alternative Project.

Cut down on the number of financial exploitation cases in nursing homes when a family member or legal representative is the suspected perpetrator. Ombudsman and stakeholders must work together to address and attempt to rectify the underlying causes of financial abuse for residents of LTC facilities.

Provide more intensive, advanced training on mental illness and mental health psycho-social needs to long-term care facility staff. Mixing the young mentally ill with the aged does not work.

### **LONG-TERM CARE OMBUDSMAN PROGRAM (MARGARET NIEDERER)**

The number of persons living in Illinois long-term care facilities who were harmed is too high. There are still too many "G" deficiencies cited during annual surveys, meaning that one or more persons were harmed, having such conditions as dehydration, malnutrition, falls because of improper use of restraints, etc. In 2001, the most recent report by the Illinois Department of Public Health revealed that over 25% of nursing homes were found to have "G" violations or higher.

The cause for neglect have been attributed to lack of staff, lack of staff training, lack of staff availability, lack of sufficient supervision of staff and inadequate administrators.

Funding is not the only factor. There is insufficient analysis of nursing home cost reports to determine if a rate increase is necessary, the amount of the increase, how to distribute additional funds, and the accountability if an increase is given.

Illinois must change from being an “institutionalized state” to one that provides a continuum of long-term care in each area of the state. Illinois spends 77% of its Medicaid funds on institutional care, compared to 35% in some other states. We must have supportive living and assisted-living-type of facilities.

■ *Don Chandro (Cooperative Healthcare Planning Services – health insurance):* More people need long-term care insurance. A long-term care tax credit would help more people purchase services and lower the state’s expense.

# **Minnesota's Long-Term Care Reform: Vision to Implementation**

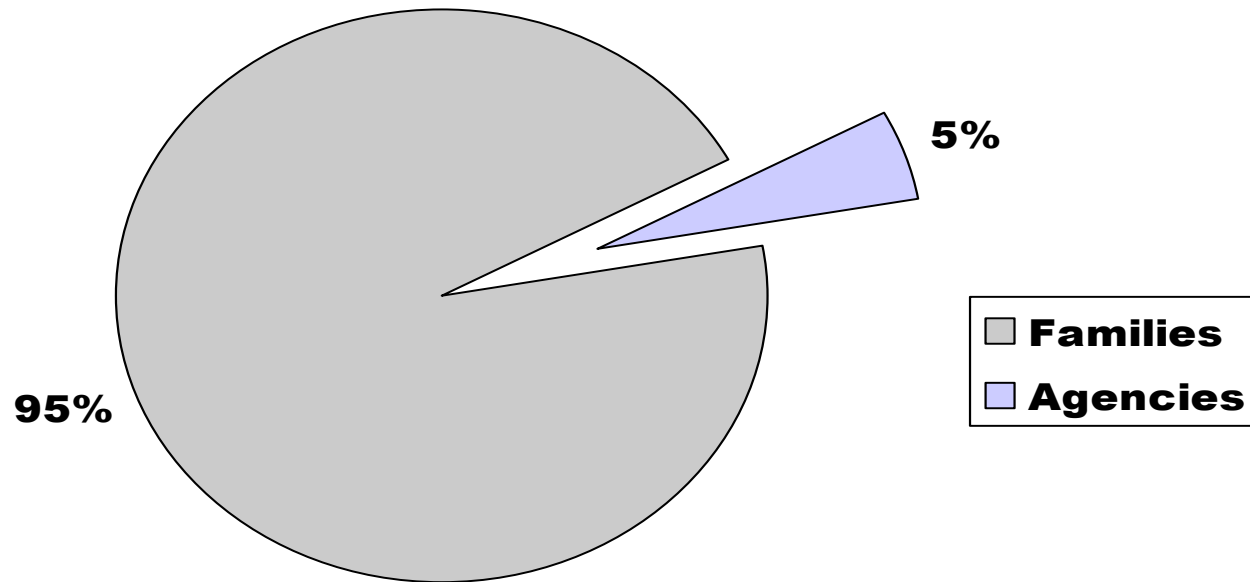
***Jim Varpness, Director  
Aging and Adult Services Division  
Minnesota Department of Human Services***

**Illinois LTC Forum — October 7, 2003**

# Who Provides Long-Term Care?

- **Long-term care can be provided in a variety of settings, not just nursing homes.**
- **The vast majority of long-term care for the elderly is provided by family members - especially spouses and daughters and daughters-in-law.**

# Who Provides Long-Term Care?



Source: Survey of Older Minnesotans, Minnesota Board on Aging, 1995

# Financing of Long-Term Care

- **Majority of long-term care that is paid for is paid with public funds.**
- **58% of all paid long-term care is publicly financed.**
- **Most of these funds are paid through the federal/state Medicaid program.**



# **Long-Term Care in Minnesota**

---

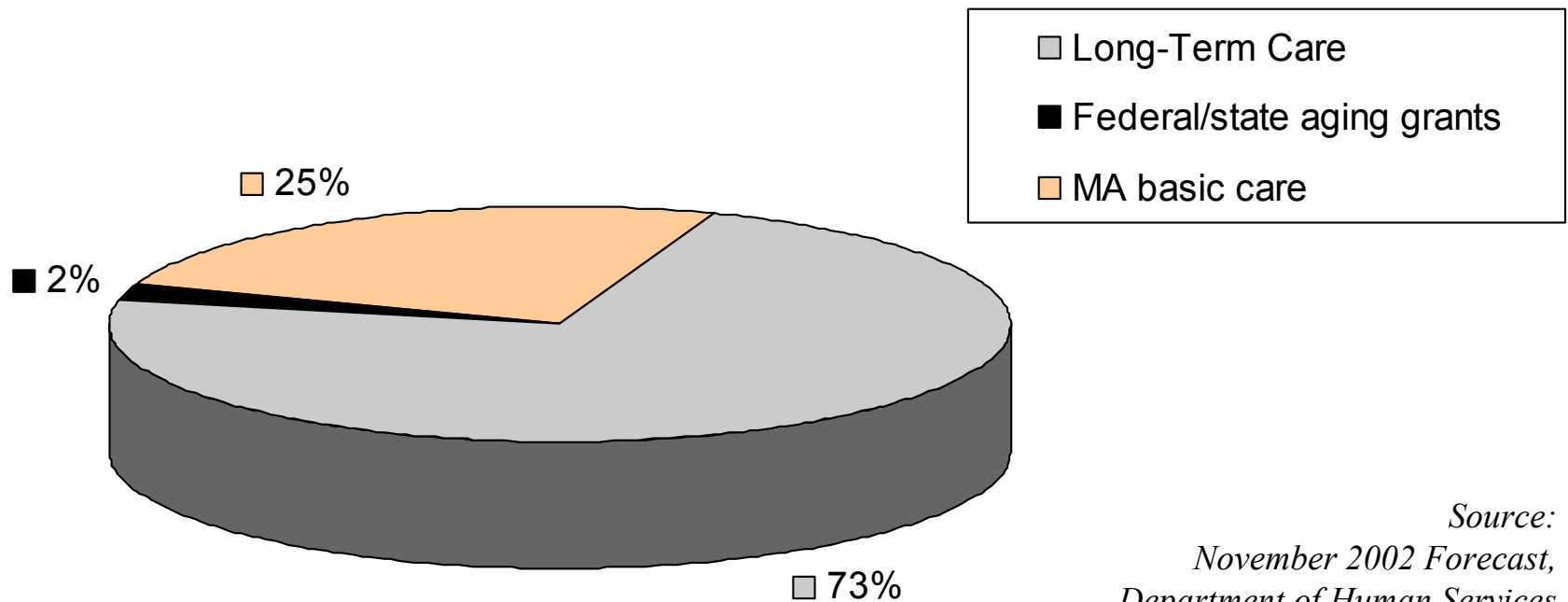
**State of Minnesota spends \$1.1 billion on long-term care for the elderly.**

- **\$890 million for nursing home care.**
- **\$250 million for community care.**

# Department of Human Services Continuing Care Administration

## DHS Expenditures to Serve Elderly Persons FY 2002

Total = \$1.4 billion (includes federal and state dollars)



Source:  
November 2002 Forecast,  
Department of Human Services

# Long-Term Care Issues

- **Minnesota Long-Term Care Task Force met in 2000 to address critical issues.**
  - **Issue: We are overly reliant on institutional model of long-term care.**
  - **Issue: Consumers prefer home and residential options.**

# **Long-Term Care Policy Directions**

- **Maximize peoples' ability to meet their own long-term care needs.**
- **Expand capacity and availability of community options.**
- **Reduce reliance on the institutional model.**

# **Long-Term Care Policy Directions**

- **Achieve quality and good outcomes.**
- **Support informal network of family, friends and neighbors.**
- **Recruit and retain stable work force.**

# **Reshaping Long-Term Care**

## **Highlights of 2001 Legislation:**

- **Expansion of information and assistance.**
- **Design of long-term care consultation services (aka pre-admission screening).**
- **Community-based services development funds.**

# **Reshaping Long-Term Care**

## **Highlights of 2001 Legislation**

- **Increased funding for Elderly Waiver and Alternative Care services.**
- **Incentives for voluntary nursing home bed reduction.**
- **COLAs for all long-term care providers.**

# **Reshaping Long-Term Care**

## **Highlights of 2001 Legislation**

- **Initiatives to strengthen long-term care work force.**
- **Initiatives to enhance quality and improve consumer satisfaction.**
- **Redesign of payment systems.**
- **Planning and development by counties and AAAs.**



# Reshaping Long-Term Care

## How long-term care reform was funded:

- **Expand community care by reinvesting money saved through voluntary nursing home closures.**
- **The reinvestment concept was necessary to gain support of Ventura administration in 2001.**

# Reshaping Long-Term Care

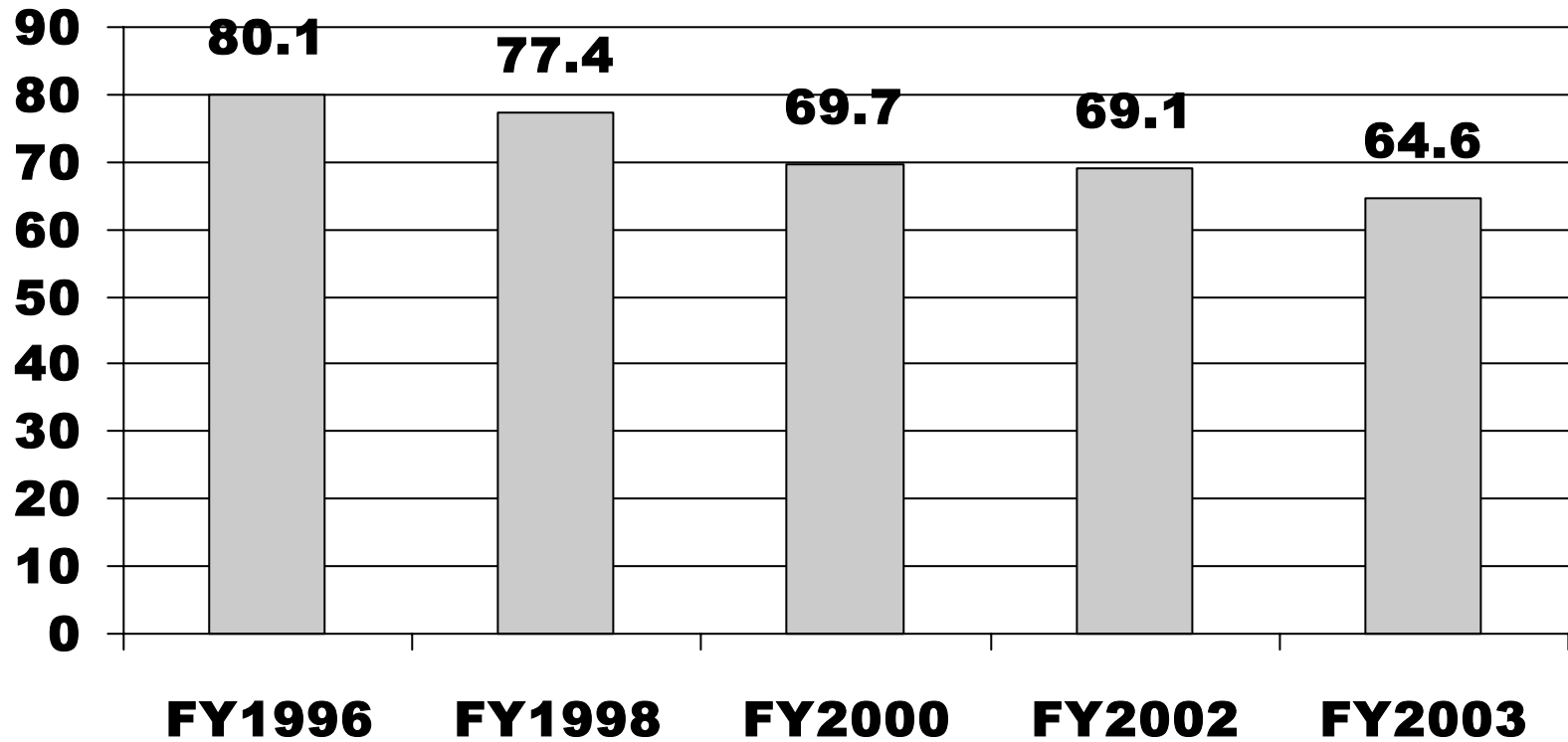
## What has really happened?

- **4,000 nursing home beds closed.**
- **Increase in use of Waiver/AC.**
- **increase in average monthly costs for community care.**
- **Information/assistance/access - MinnesotaHelp.info® & Senior LinkAge Line®.**

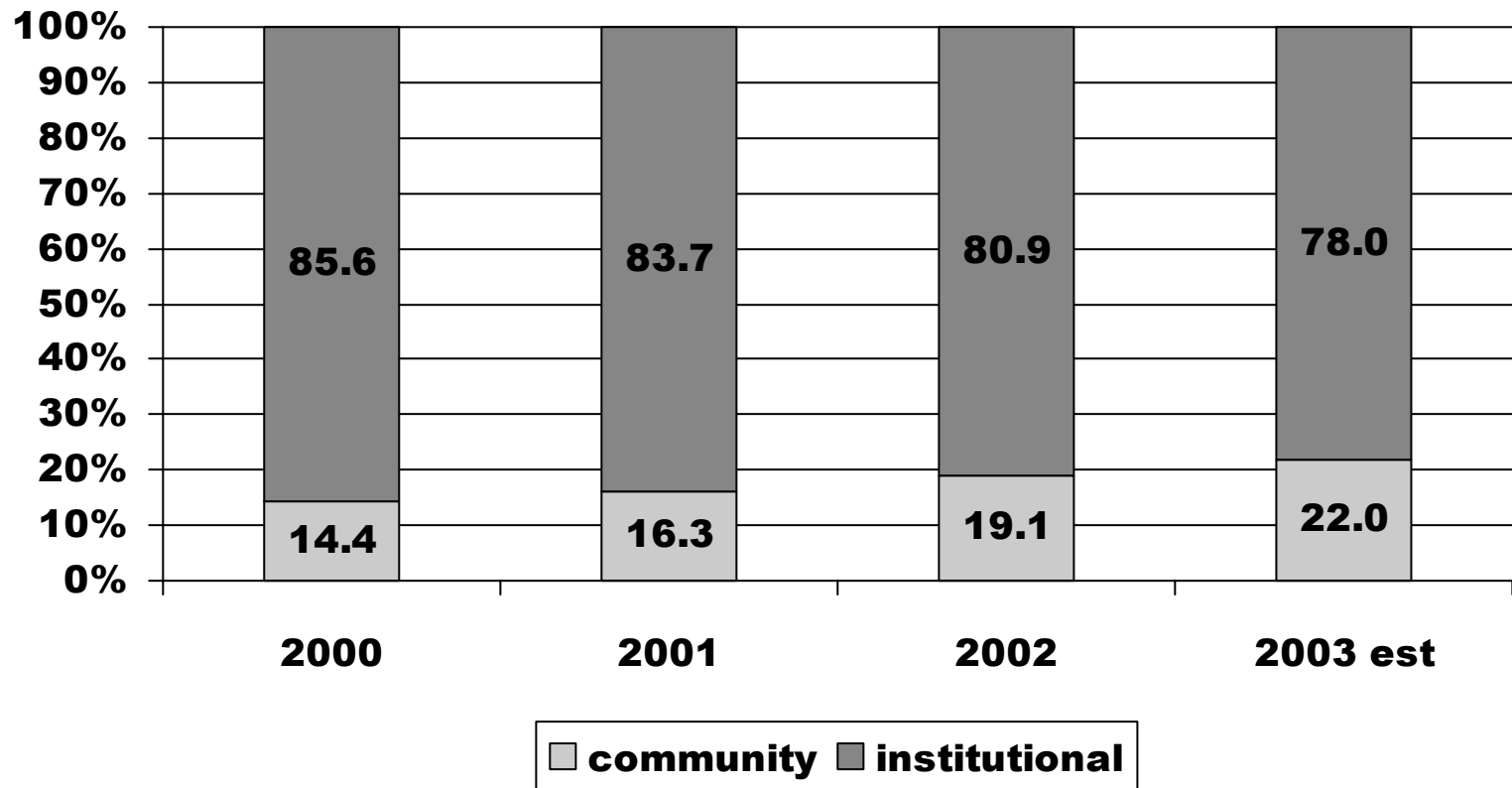
# Long-Term Care Benchmarks

- **Benchmarks provide method for regularly measuring progress of reform efforts:**
  - **12 benchmarks included in the task force report;**
  - **5 benchmarks measure progress in “balancing” the long-term care system**
- **Idea for benchmarks came from LTC State Profiles by Kane, Kane, Ladd (1999)**

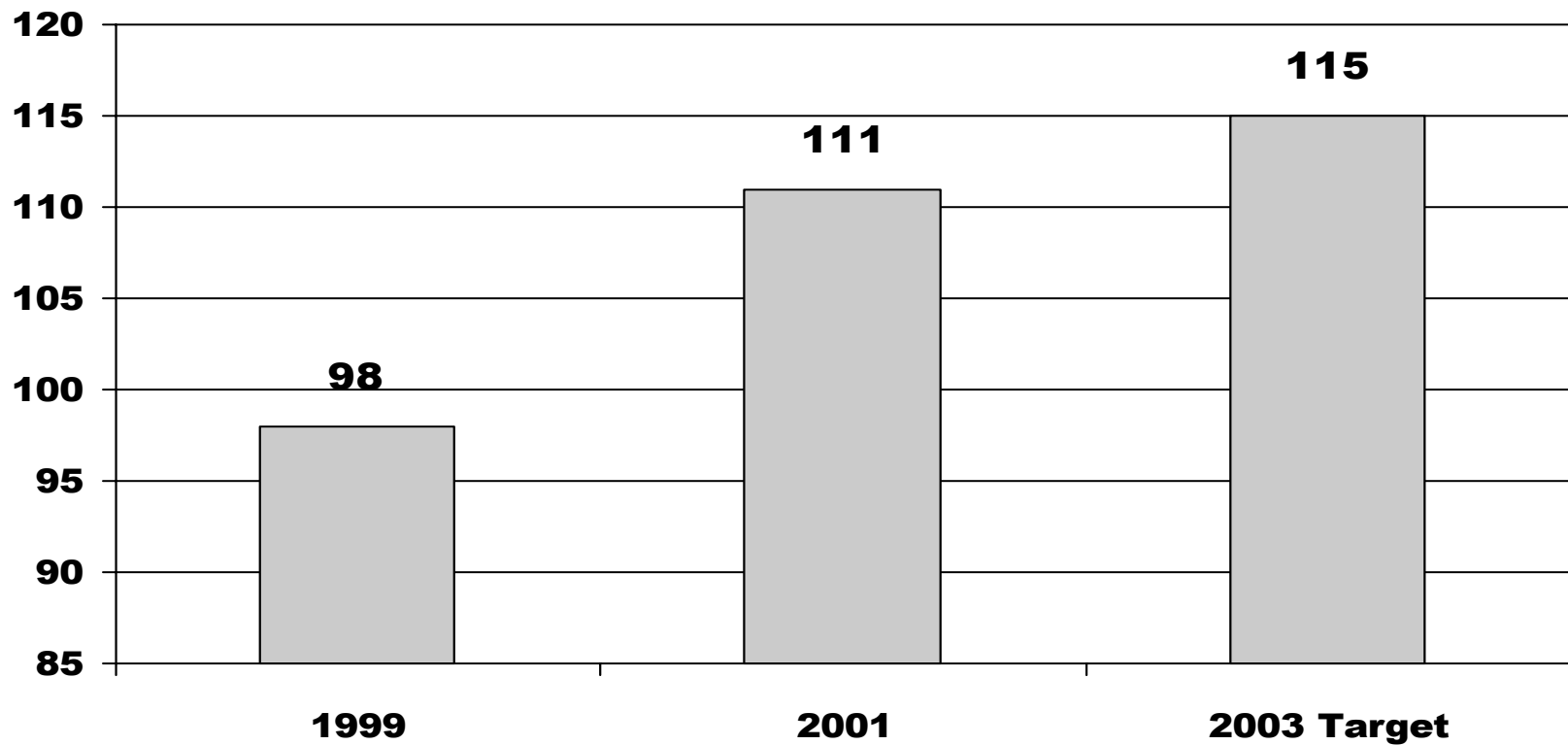
# Ratio of Nursing Home Beds/1,000 Persons 65+



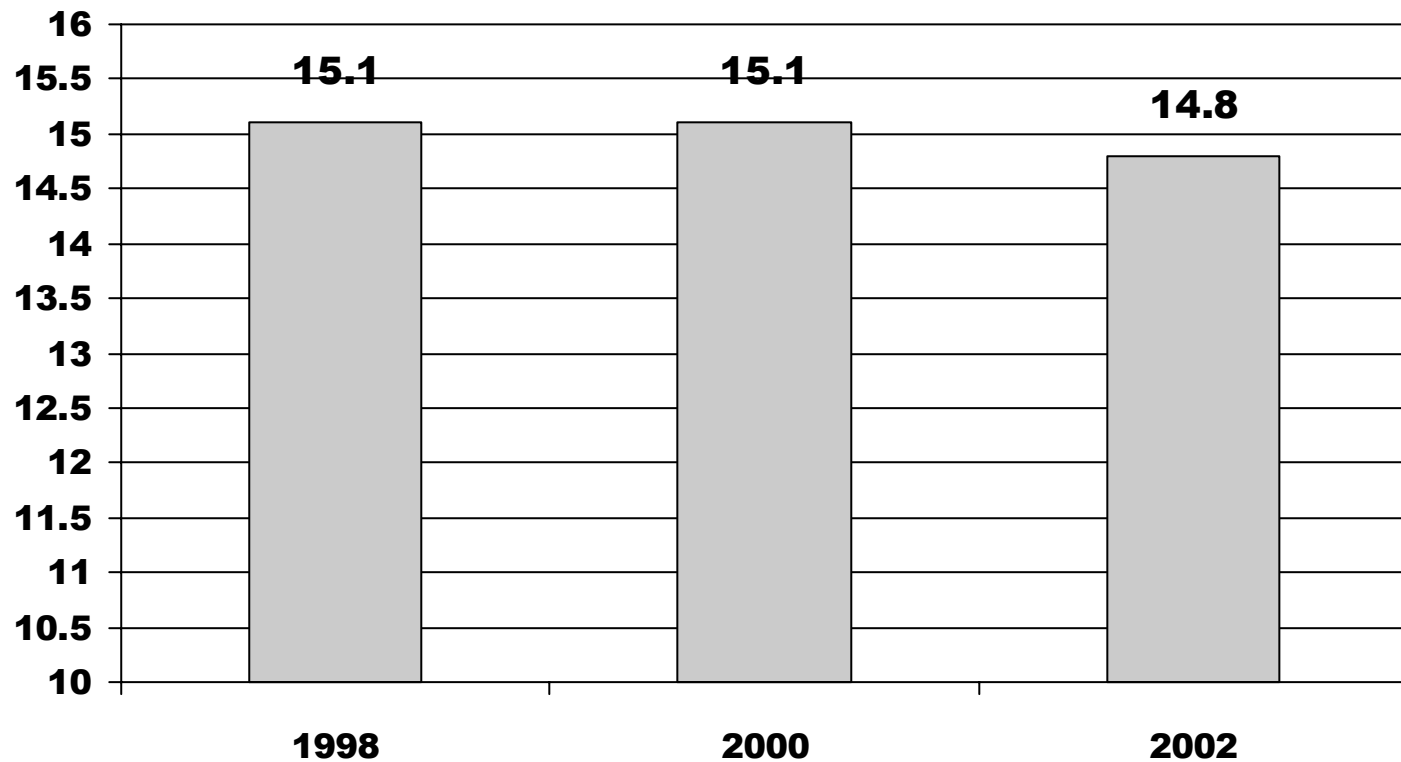
# Percent of Public LTC Spending on Elderly for Institutional/Community Care



# Number of “supportive housing” units/1,000 persons 65+

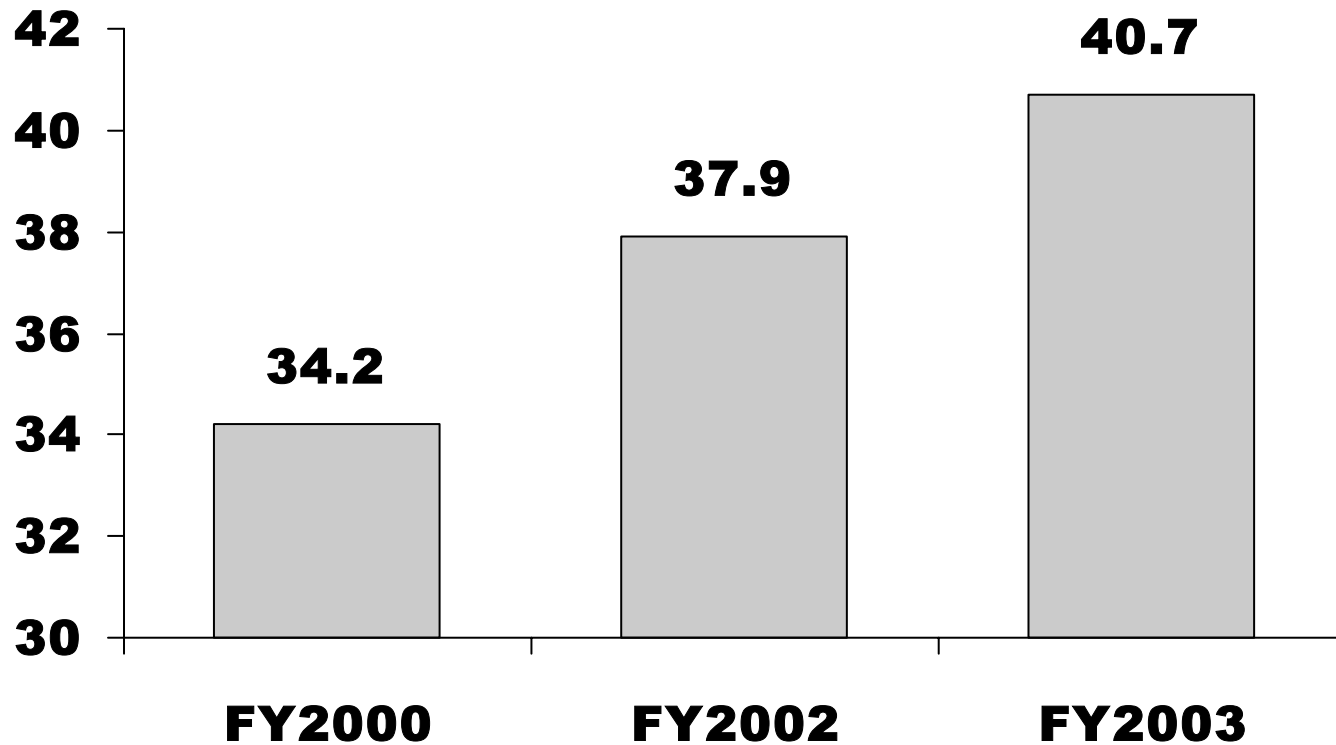


# Percent of older persons in nursing facilities that is case mix A (less disabled)\*



*\*Less disabled includes persons with fewer functional problems who are classified as case mix A, on a scale of A to K.*

# Percent non-case mix A elderly in Elderly Waiver programs





# Other Measures of Success

- **Paradigm has shifted from “nursing home” to “staying in the community”.**
- **Counties are transforming the way they serve elderly persons.**
- **Volunteer and community resources are more closely linked to formal long-term care services.**

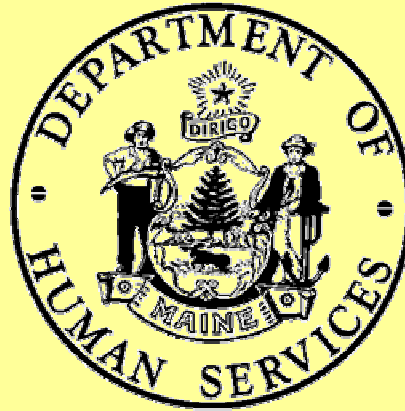
# Conclusions

- **Public financing will continue to be major payer for LTC.**
- **Private options are growing but will never close the gap.**
- **We are shifting more and more to community/consumer-directed care.**
- **Need to maintain LTC reform principles, measure progress, take opportunities that arise.**

# Conclusions

---

- **Promoting non-government financing options.**
- **Expanding information, assistance, and support for family caregivers.**



# Long-term Care Reform Maine's Experience

---

***Goal: Reduce reliance on institutional care as the principal means of providing long-term supports for elders and adults with disabilities***

***Summit on Senior Services***

***October 7, 2003***

# Principles of Reform

## **★Choice**

Offer more choice of residential and community-based services for consumers and families.

## **★Equity**

Eliminate disparities in statewide allocation/utilization of in-home care resources.

## **★Cost-effectiveness**

The right care, at the right time, in the right setting, at the right price.

# Budget Deficit: An Opening for Reform

- 1993:** Nursing home spending up; extensive waiting list for home care; no residential alternatives to institutional care.
- 1994:** Legislature tightens Medicaid nursing home admission criteria; use savings for home care and state budget deficit. Adopts budget neutrality for any nursing home certificate of need projects.
- 1995:** Legislature adopts mandatory pre-admission screening for all nursing home admissions.
- 1996:** Redesign administration of public home care programs to reduce overhead costs and address disparities in service allocation.
- 1998:** Implement MECARE on-line, electronic system for LTC eligibility determination.
- 1995 — 2003:** Revise regulations for all public LTC programs to promote choice, equity, and cost-effectiveness.
- 2002 — :** Budget crisis redux.

# What's Working

- 39% of LTC budget goes to home & community care — up from 16% in 1995.
- Doubled number of persons using home care and assisted living.
- Medicaid nursing home census down by 17%; discharges to home tripled; length of stay reduced.
- More than 2000 nursing home beds (20% of total) “banked” or de-licensed; others converted to assisted living.
- Slowed growth in LTC spending.
- Per person LTC spending declined 12%.

# What Got Us Here

- Deficit continued long enough to allow reforms to work.
- Strong leadership from key legislators, Governor, and Commissioner.
- Support from senior and disabled consumers.
- One agency manages single assessment for range of programs.
- Restructure administration of home care programs.
- Medicaid funding for residential alternatives to nursing homes.
- Changes to nurse delegation rules.
- Competent and persistent staff work.



# Other Essential Ingredients

- Good data systems.
- One department manages regulatory agenda.
- No county government.
- Acuity-based payment.
- Partnership with university for evaluation.

# Challenges

- Labor shortage.
- Balancing equity and flexibility.
- Rising expectations.
- Managing high acuity consumers at home.
- Waiting list for state-funded home care services.