

M^{LTC}onitor

SPRING 2005 THE LONG TERM CARE ADVOCATES' NEWSLETTER

Coalition Issues 2004 Report Card for New York on Long Term Care

The state of long term care in New York had both high and low points in 2004. Perhaps the greatest achievement was the passing of the Assisted Living Reform Act, which will provide good protections for people in assisted living and alleviate much of the confusion which has existed in the marketplace. Unfortunately, the state did little else to protect consumers: bills to improve staffing in nursing homes languished, adult home reforms were curtailed and Medicaid beneficiaries were besieged by attempts to cut benefits.

Following is a year end assessment of how New York's leaders performed in 2004.

Governor Pataki: B-

The Governor played a key role in the major achievement in long term care in 2004 — passage of a good assisted living law. His leadership on this important issue would merit an "A" if not for the several important areas in which the Governor and his office did not work to protect consumers.

In particular, the achievement of assisted living protections must be weighed against the state's continuing failure to protect nursing home residents by passing one of two important bills: the "Safe Staffing" bill, which would require minimum levels of direct

LONG TERM CARE COMMUNITY COALITION	REPORT CARD
Governor Pataki	B-
Assembly	B+
Senate	C-
Attorney General Eliot Spitzer	A
Center for Medicare and Medicaid Services (CMS)	A
New York State Department of Health (DOH)	C-

See last year's report card in Winter 2004 Monitor on our website.

care staff, and the Nursing Home Diversion Act, which would prevent nursing homes with dangerously low staffing from taking in additional residents until they improve. As our executive leader, it is up to the Governor to take up these critical causes in order for them to be achieved. Unfortunately, he failed to do so, and too many vulnerable residents across the state continued to suffer needlessly.

Not only did the Governor not take the lead in making desperately needed improvements, his actions made consumers even more vulnerable. The Governor took steps to limit Medicaid benefits, a critical safety net for long term care consumers and their families by trying to change the rules on spousal refusal and the look back period for Medicaid eligibility. He appears to be moving forward with plans to allow poorly trained and supervised feeding assistants in nursing homes. His Health Care Reform Working Group Interim Report made cost savings and "efficiencies" a principal goal, while ensuring safety and good care took a back seat. His Department of Health continues to fail to properly oversee nursing home care (see separate listing for Department of Health, below). And while we hope that the Governor's proposed single point of entry system for long term care will benefit consumers, we are very concerned that it could harm consumers.

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Coalition Issues Report Card ...

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Summary: While we were thrilled that the Governor took the lead on assisted living, his failure to protect nursing home residents through either legislation or oversight means that too many residents continue to suffer needlessly in New York.

Assembly: B+

The Assembly continues to be the leading force in Albany protecting consumers. The major achievement of the year — passage of assisted living protections — would not have been possible without the hard work and perseverance of Aging Committee Chair Steve Englebright and his staff, and the support of Health Chair, Richard N. Gottfried.

On nursing home issues, the Assembly made progress but failed to push forward concrete improvements. The Safe Staffing Bill continued to be moribund. However, the Nursing Home Diversion Act, an important emergency safety measure introduced by Health Committee Chair Richard Gottfried, garnered over two dozen additional co-sponsors during the session.

Summary: Moving in the right direction thanks to work of Health and Aging Committee Chairs, but real progress will require commitment of Speaker and general membership to protect consumers and reform a system that too often harms those it is supposed to be helping.

Senate: C-

After reports that Senate representatives walked out on negotiations for assisted living reform last year, we were glad to see that the entire Senate came together and unanimously ratified the assisted living bill at the end of this session. Unfortunately, this was the beginning and end of the Senate's actions to protect long term care consumers. Nothing was done to help people in nursing homes, among our state's most vulnerable citizens.

Summary: Passage of assisted living protections is a major step forward for long term care in New York, but one has to wonder why the Senate is not taking a leadership role in protecting vulnerable consumers. Thousands of lives are at stake and millions of dollars are spent each year to provide care — why isn't the Senate leadership working to protect consumers? Where is the outrage over widespread poor care?

Attorney General Eliot Spitzer: A

This year the Attorney General established a Patient Protection Section within his Medicaid Fraud Control Unit (MFCU) to respond to allegations of patient abuse and neglect in the state's nursing homes. In addition to

investigating and prosecuting acts of patient abuse and neglect, the Patient Protection Section scrutinizes available information for evidence of institutional abuse and neglect, and works to achieve institutional and regulatory reform to better protect nursing home residents.

Summary: Once again, the Attorney General has taken the lead in making concrete improvements to nursing home care in New York.

Centers for Medicare and Medicaid Services (CMS): A

CMS Region II, overseeing New York State Department of Health (DOH) regulatory role, did a number of things this year to better protect nursing home residents in New York State. After watching DOH cite the Northeast Center for Special Care in Lake Katrine for putting its residents in jeopardy for years without levying fines, CMS finally stepped in and inspected the home itself. It levied a federal fine of \$62,000 and terminated the home from the Medicare and Medicaid programs. (The facility won its appeal overturning its termination; CMS may appeal this decision). In addition, CMS began this year to levy federal fines against a number of other homes (see Enforcement Actions in this newsletter).

Summary: CMS continues to pick up the slack on New York's enforcement of crucial regulations.

New York State Department of Health (DOH): C-

Although we are happy to see DOH has improved its enforcement actions this year (it fined 84 homes this year compared to 37 last year), it still does not seem willing or able to remove poor providers with a history of giving poor care and replace them with a receiver or with a new operator. *The Monitor* has in the past written stories about this issue. A classic example of this was seen this year with the Northeast Center. While CMS terminated the Northeast Center from the Medicare and Medicaid programs, DOH, not only, according to information received from DOH, did not fine the home, it made sure the facility could continue to give care. Rather than find a new operator of this home after years of it going in and out of compliance with standards of care and putting its residents in jeopardy, DOH continued their Medicaid funding to the tune of 4.6 million dollars. (The home is now back in compliance and has won its appeal overturning its termination). In addition, DOH's ability to investigate and substantiate complaints is still very poor. We have seen little progress in this area.

Summary: DOH continues to have problems holding nursing home providers accountable for poor care. □

Implementing the Medicare Law: Trouble for Nursing Home Residents

Readers of *The Monitor* will recall that in our Winter 2004 edition we listed a number of general concerns we had with the new Medicare Prescription Drug Act signed into law by President Bush on December 8, 2003. The law creates a new Part D through which Medicare beneficiaries may receive help paying for their prescription drugs.

“This could be disastrous for nursing home residents.”

Regulations implementing provisions creating Part D have now been proposed by the Centers for Medicare and Medicaid Services (CMS). It is clear that these raise many issues for nursing home residents. This article refers to points made by Vicki Gottlich of the Center for Medicare Advocacy and to comments made by the National Citizens Coalition for Nursing Home Reform (NCCNHR).

According to Ms. Gottlich, nearly all residents of long-term care facilities will be affected by the new law and because of their health and economic status as well as the setting in which they live, nursing home residents will experience many problems in choosing and then enrolling in a Medicare prescription drug plan. They may have fewer drug plan choices than other Medicare beneficiaries; the pharmacies they use may not be included in their drug plan's pharmacy network; and they may have difficulty in getting the medications they require.

Problems in Choosing and Enrolling in a Drug Plan

1. The process of choosing and then enrolling in a drug plan and applying separately for a low income subsidy will be difficult for many nursing home residents with cognitive and/or physical impairments. The law requires that if a dual eligible resident (i.e., eligible for both Medicare and Medicaid) does not choose a plan, he will automatically be enrolled in a plan. However, there is no provision for automatically enrolling other residents who may not be capable of

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New Guides for Assisted Living Consumers and Staff to Help Fulfill Promise of Assisted Living

Aging Americans want the independence and choice that assisted living facilities promise, but experts say that reality often does not live up to their expectations. According to LTCCC and the Coalition of Institutionalized Aged and Disabled (CIAD, a Coalition member), which have extensively studied assisted living arrangements throughout the nation, staff and managers of assisted living environments are committed to making the facilities meet the residents' desires, but often have a hard time doing so. Conflicting needs and ideas of residents, their children, managers and other staff can make it difficult to create a lifestyle that is 'just like home' for residents. Although fulfilling the promise of assisted living can be hard to achieve, experts say with the right tools, it can be done.

"We know that satisfaction is increased when residents maintain their independence, ability to make decisions and control over their own life and are able to clearly express their expectations to staff and family members," says Cynthia Rudder, PhD, LTCCC's executive director. "We also know that assisted living staff and managers really want to make all of these things happen for their residents, but it's not easy for them. There are many legitimate concerns and obstacles that must be overcome."

With funding from the Robert Wood Johnson Foundation, LTCCC and CIAD developed four resource guides to empower assisted living residents, staff and consumers to create environments that offer independence, choice and control for residents. The new resource guides aim to effectively maximize residents' living experiences by facilitating discussion



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Implementing the Medicare Law...

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choosing for themselves. In addition the proposed regulations do not clarify who has authority to act when the eligible individual cannot do so. And, although the regulations concerning the low-income subsidy do allow a personal representative to apply for the subsidy on an individual's behalf, there is no provision for residents who have no one who will or can act on their behalf. LTCCC agrees with NCCNHR's recommendation that a procedure for enrollment of these residents must be developed. In addition, we agree that grants and other resources should be made available to help community-based organizations assist residents who need help in choosing a plan.

2. Full dual eligibles in nursing homes will lose their Medicaid drug benefit on January 1, 2006 because Medicare will provide these benefits once a plan is chosen. However, the automatic process for these residents who do not choose by themselves will not occur until May 15, 2006. This will probably lead to gaps in coverage for many residents. We agree with NCCNHR's suggestion that transition of coverage should be delayed by at least six months and preferably for a year.

Problems Related to Access to Medications

1. Currently over 80% of all nursing home beds in the country are in facilities that require their residents to use a long-term care pharmacy. Nursing home residents should not have to pay higher costs because they are unable to choose their pharmacy. NCCNHR proposes that all drug plans be required to contract with all LTC pharmacies or residents must be exempt from any cost-sharing requirements (such as co-pays) for using an out-of-network pharmacy. LTCCC strongly agrees.

2. In order to promote cost-saving mechanisms, the law permits each drug plan to develop its own formulary. [A formulary is a list of drugs and their dosages that will be covered.] The statute contains no requirements for providing greater access to drugs used by nursing home residents and other vulnerable populations that may not be on the formulary. This could be disastrous for nursing home residents. NCCNHR strongly supports the recommendation of the Medicare Consumers Working Group (see,

http://www.medicareadvocacy.org/Reform_ActWorkingGroupComms.htm) that provisions must be made for alternative, flexible formularies for long term care residents that would include coverage for all FDA-approved covered Part D drugs with a valid prescription. We agree.

Finally, we agree with the NCCNHR recommendation that assisted living facilities that have dual eligibles as residents should be defined as long term care facilities and that all the suggestions be put in place for them as well. For more information on all of these issues, see "Issues for Medicare Beneficiaries in Long-Term Care Settings: An Analysis of the MMA and Proposed Regulations," available at <http://www.kff.org/medicare/7161.cfm>. Full comments by NCCNHR can be seen at: <http://www.nccnhr.org>.

By the time this edition of *The Monitor* has been printed, the final regulations may have been made public. If the proposed regulations have not been changed, we will need to work with the New York State Department of Health to help deal with some of these issues. Look to future editions of this newsletter, and the LTC E-Newsletter, for updates. □

2005 Coalition Meeting Schedule

LTCCC holds general Coalition meetings on a bi-monthly basis. We discuss new issues, report on Coalition activities and plan strategy. Often there is a speaker who presents on a pertinent long term care issue.

Following is the meeting schedule for the rest of 2005: March 28, May 23, July 25, Sept. 26, December 28

These meetings are held at the offices of AARP New York and are open to all Coalition members. For more information on joining the Coalition or attending meetings, please call Barbara at 212-385-0355. If you are a member and would like to attend a meeting please call or email us (barbara@ltccc.org) at least one week in advance so that we can add your name to the list for building security. □

EPIC WORKS: Seniors & Disabled United for EPIC

The LTCCC joined with over 50 organizations throughout New York in the EPIC WORKS: Seniors & Disabled United for EPIC campaign to ensure that the elderly and disabled will get the drug coverage they need when the new Medicare Part D prescription drug program goes into effect in January 2006. Started in 1987 after several years of hard fought grassroots

“We call on Governor Pataki, Majority Leader Bruno and Assembly Speaker Silver to use the EPIC WORKS principles to make sure that the new Medicare law does not harm New Yorkers.”

advocacy, EPIC (Elderly Pharmaceutical Insurance Coverage) provides affordable, comprehensive drug coverage to 345,000 New York seniors. EPIC benefits and its cost-effective administration are threatened by the flawed, complicated new law that favors private prescription drug plans (PDPs) over state pharmaceutical assistance programs (SPAPs). State action will be required to protect current enrollees from this flawed benefit and to include people with disabilities in EPIC who also need this coverage.

We call on Governor Pataki, Majority Leader Bruno and Assembly Speaker Silver to use the EPIC WORKS principles (listed below) to make sure that the new Medicare law does not harm New Yorkers. No one should be forced into enrolling in a Part D plan that has major gaps in coverage, higher cost-sharing and reduces access to pharmacies. While the Medicare Part D drug program provides increased access for Medicare beneficiaries who currently lack any coverage, it will be a substantial net loss for many in New York, especially for current EPIC and dually eligible Medicare/Medicaid enrollees. Although there are significant subsidies for those with very low incomes and assets, they may not have access to needed medications because of the variations and limits allowed to the PDP formularies and pharmacy networks.

New York's elected leaders are now faced with

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Special Action Alert... Urge NY Leaders Who Supported Assisted Living Reform to Protect Nursing Home Residents

As readers of *The Monitor* know, the Coalition worked hard last year for an Assisted Living Law that had real consumer protections. With the help of many people who spoke out — sending letters and faxes, making phone calls — an assisted living law passed with unanimous support in both the NY Assembly & Senate.

Unfortunately, the state leaders failed to come together to pass a law to protect nursing home residents, our most vulnerable citizens. The crisis in nursing home care has continued unabated. Now that all the leaders have come together on assisted living, we believe the time is ripe for nursing home reform.

“Now that all the leaders have come together on assisted living, we believe the time is ripe for nursing home reform.”

Please take a moment now to contact your legislators and Governor Pataki and let them know that you care about nursing home residents and want to see state action to protect them this year. You can go to the Citizen Action Center on our website to send a free fax or email at www.ltccc.org, or see the back page of the newsletter for other contact information.

Following is an excerpt from the letter LTCCC sent to every member of the Senate and Assembly. Please feel free to reference it when you write or call your legislator.

On behalf of the Long Term Care Community Coalition, which has been working to improve care of the elderly and disabled in New York for over two decades, I am writing to you not only to thank you for standing up for assisted living consumers, but also to ask you to take a stand to help the very vulnerable people in nursing homes in our state.

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ENFORCEMENT ACTIONS AGAINST NURSING HOMES¹

STATE ENFORCEMENT ACTIONS AGAINST NURSING HOMES: 9/16/04-12/15/04

The State Fined 29 Nursing Homes

NAME OF HOME	LOCATION	DATE OF SURVEY	AMOUNT
Adventist NH	Livingston	11/21/03	2,000
Betsy Ross Rehab Ctr.	Rome	11/14/02, 10/30/03	4,000
Carthage Area Hosp.	Carthage	07/30/04	2,000
Cedar Lodge NH	Center Moriches	07/28/03	2,000
Fieldston Lodge	Bronx	08/25/04	4,000
Goldcrest Care Ctr.	Bronx	10/27/03	2,000
Grace Manor HCF	Buffalo	02/27/03, 11/28/03	4,000
Groton Community Health	Groton	12/10/03	2,000
Highlands Living Ctr.	Pittsford	09/12/03	2,000
Hill Haven NH	Webster	03/19/04	2,000
Katherine Luther NH	Clinton	02/13/04	2,000
Martin Luther NH	Clinton	02/13/03	2,000
Masonic Home and HCF	Utica	03/30/04	2,000
Meadowbrook Care Ctr.	Freeport	10/30/03	2,000
Mercy Health & Rehab	Auburn	06/06/03	4,000
Morningside House	Bronx	04/07/03	2,000
Northwoods, Cortland	Cortland	06/26/03, 03/11/04	3,000
Orchard Manor Inc.	Medina	03/05/03	1,000
Orleans Cty NH	Albion	06/26/03	2,000
Orleans Cty NH	Albion	11/18/03	1,000
Our Lady of Consolation	W. Islip	08/08/03, 11/07/03	2,000
Our Lady of Consolation Geriatric Care Ctr.	W. Islip	02/10/04	1,000
Pearl & Everett Gilmour	Norwich	02/27/03	3,000
Riverview Manor NH	Owego	08/05/03, 01/30/04	6,000
Shorefront Jewish Geriatric Ctr.	Brooklyn	09/10/02	1,000
St. Teresa's NH	Middletown	08/28/03	2,000
Sullivan Cty. Adult Care Ctr.	Liberty	02/18/04	1,000
Tioga Nursing Facility	Waverly	05/22/03	3,000
Village Ctr. For Care	NYC	04/30/03	2,000
Waterview Hills Nursing Ctr.	Flushing	12/19/02	2,000
Wayne Health Care	Newark	02/11/04	1,000

¹ As reported by the Department by Health. This list will be posted on LTCCC's website every three months, two to three weeks after the end date listed above. If you want to know why a facility was cited and/or fined, you can get a copy of the Statement of Deficiencies (SOD) from the Department of Health. You will be charged \$.25 a page. Call Jim O'Meara, FOIL Officer - 518-474-8734 or e-mail - nhinfo@health.state.ny.us. Ask the Department to let you know how much it will cost to make sure that you can afford the amount. If you cannot, ask if you can look at the SOD in your regional office.

If the nursing home was found, at the time of the survey, to have given substandard quality of care (SQC) and/or to have put residents in immediate jeopardy (IJ), (the most serious level of deficiencies).

The State Took Other Actions at 9 Nursing Homes

NAME OF HOME	LOCATION	IJ, SQC or G	SURVEY DATE	ACTIONS ¹
Bayview NH	Is. Park	IJ/SQC	11/12/04	DOPNA, POC, In-Service, State Monitor
Franklin Cty NH	Malone	IJ/SQC	9/29/04	DOPNA, POC, In-Service, State Monitor
Lake Shore NH	Irving	IJ/SQC	12/9/04	DOPNA, POC, State Monitor
Morningside House	Bronx	IJ/SQC	10/29/04	DOPNA, POC, In-Service, State Monitor
Morris Park	Bronx	IJ/SQC	9/20/04	DOPNA, POC, In-Service, State Monitor
Ocean Promenade	Rockaway Park	IJ/SQC	9/13/04	DOPNA, POC, In Service, State Monitor
Riverhead NH	Riverhead	IJ/SQC	9/16/04	DOPNA, POC, In-Service, State Monitor
Sheridan Manor	Tonawanda	IJ/SQC	9/22/04	DOPNA, POC, In-Service, State Monitor
St. Patrick's Home	Bronx	IJ/SQC	9/14/04	DOPNA, POC, In-Service, State Monitor

¹**Denial of Payments for New Admissions (DoPNA):** Facility will not be paid for any new Medicaid or Medicare residents until correction; **Directed Plan Of Correction (POC):** A plan that is developed by the State or the Federal regional office to require a facility to take action within specified timeframes. In New York State the facility is directed to analyze the reasons for the deficiencies and identify steps to correct the problems and ways to measure whether its efforts are successful; **In-Service Training:** State directs in-service training for staff; the facility needs to go outside for help; **State Monitoring:** State sends in a monitor to oversee correction; **Termination** means the facility can no longer receive reimbursement for Medicaid and Medicare residents from the Federal Government.

FEDERAL ENFORCEMENT ACTIONS AGAINST NURSING HOMES: 1/1/04-12/15/04

The Federal Government Imposed Civil Money Penalties (CMPs)¹ On Five Nursing Homes²

NAME OF HOME	LOCATION	IJ, SQC or G	AMOUNT
Bellhaven Center	Brookhaven	IJ, SQC	\$28,000
Episcopal Church Home	Rochester	IJ	\$42,000
Morris Park	Bronx	IJ	\$103,000
Northeast Center for Special Care	Lake Katrine	IJ	\$95,700
Patchogue Nursing Center	Patchogue	IJ	\$116,000

¹**Civil Money Penalties (CMPs)** - States can collect CMP funds from nursing homes that have failed to maintain compliance with Federal conditions of participation in Medicare and Medicaid programs. At this time, New York State does not collect such funds because we have only recently changed a law that would put us in violation of federal law. The federal law requires that if CMPs are collected they must be put into a special fund and used for the protection of the health or property of residents of nursing facilities. New York State had a law that requires all fines collected to be returned to the state's general fund. We expect NY to levy these in the future.

²These fines are not a final determination. Before a final determination of the amount of fine is made, a facility has the right to either request a hearing before an administrative judge, or to waive its right to a hearing for a 35% reduction in the CMP amount.

The Federal Government Made a Final Determination of CMPs for Three Homes

NAME OF HOME	LOCATION	DATE	AMOUNT
Bethel Nursing & Rehab	Croton on Hudson	11/30/04	\$10,000
Good Samaritan	Sayville	5/20/04	\$5000
RiverMede	Binghamton	10/1/04	\$230,750

In addition, CMS has imposed fines per day on Fieldston Lodge (Riverdale) and Ocean Promenade (Rockaway Park). The final fine tabulation will not be levied until they achieve substantial compliance. Look for this new feature in future issues of *The Monitor*.

New Guides...

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between assisted living staff and residents, and offering solutions that will further independence for residents.

- The Guide For Potential Residents helps potential residents and their families choose an assisted living community that is the right fit for the resident.
- The Guide For Current Residents helps people already in assisted living assess whether their residence meets their expectations and suggests ways to work with staff and other residents to make it better.

- The Guide For Assisted Living Managers helps managers make their management vision a reality, by providing practical tips and case studies that help staff meet residents' needs and overcome typical obstacles.

- The Guide For Assisted Living Direct Care Staff is a unique resource that recognizes that staff members know the residents the best and can implement changes to create the most satisfying environment for the residents.

These easy-to-use resource guides that help residents' and staff maximize the assisted living experience are available free of charge at www.assisted-living411.org. They are also available in the publications section of the Coalition's website, www.ltccc.org.

"Unlike other guides, these provide practical advice for those who have the most influence over creating independence, choice and control in an assisted living situation, specifically potential and current residents and their families, managers and staff," says Geoff Lieberman, executive director of CIAD. "A variety of obstacles exist that hinder a resident's ability to lead an independent lifestyle. These guides aim to initiate further discussion about these

obstacles and concerns and offer solutions for overcoming most of them."

For example, many residents have no involvement in the decision-making process when it comes to choosing an assisted living facility. Often family members make decisions that their loved ones are perfectly willing and able to make and sometimes these decisions are not ones the resident would have made. The Guide for Current Residents suggests ways residents can work with staff to create an environment of choice that meets residents' needs while the Guide for Direct Care Staff helps staff respond to these requests and those of the family.

All guides were reviewed by a professional advisory board and were pilot-tested in diverse communities across the nation. □

Are You Concerned About Social Security? Do Rx Drug Prices Give You Heart Burn??

LEARN — THEN ACT!

Learn how to get involved in the legislative process and make an impact on our government. The Joint Public Affairs Committee for Older Adults' Institute For Senior Action (IFSA) is a 10 week course offered twice a year and open to individuals 55 and older. The classes focus on a wide variety of subjects including navigating the federal, state and local legislative processes, public speaking, writing, learning senior entitlements and much more. In the last eleven years, JPAC has offered the training on 21 occasions, graduating nearly 500 senior leaders!

The Spring session begins on Friday, March 11th and is held on Fridays from 10:00am - 2:30pm through May 27th at Teamsters Local 237, 216 West 14th Street (7th & 8th Ave).

For an application, or more information on the Institute, please contact Molly Saiger, JPAC Director at (212) 273-5260. □



LTCCC Committees Hold Summit Meeting

Three LTCCC Committees held a summit meeting in January to address the future of Long Term Care in New York State. These Committees — Assisted Living, Nursing Home Staffing and POE/Access to Care Committees — came together to assess the ramifications of the new assisted living law, possible Medicaid changes and the state's plans for a single point of entry for long term care (POE) on long term care consumers.

Passage of the assisted living bill over the summer means that there will be significant changes in the future, with mandatory licensure and increased state oversight. Coupled with Governor Pataki's continuing to move on plans for a POE, and his call for cuts to Medicaid, many of us have been concerned about how consumers will be protected as changes are put in place.

The summit began with a presentation by Martin Sobel, graduate student at NYU's Wagner School and LTCCC intern, who has been conducting in-depth research into other states' experience with a POE and the impact of those programs on consumer care. Martin's research will be part of a major report on national experience with POEs that LTCCC will be releasing early this year (see the next edition of *The Monitor* for more information). Martin reported on some of the successes and failures that he has come across in different states' programs.



This information provided the basis of a discussion on where we saw the state moving on POE and long term care in general. Most importantly, it enabled us to lay the groundwork for our plans to make sure consumers are protected in the future. We formulated



questions for Neil Lane, Acting Director of the NY State Office on Aging, who is expected to speak at our next Coalition meeting on March 28.

Major issues identified at the meeting include:

- What will happen to nursing home residents if more people are able to avoid nursing home placement by staying in the community or go to assisted living? We are especially concerned that the most vulnerable people would be left in nursing homes while resources are diverted to other care settings.
- Will assessments be mandatory in the POE?
- What agency will have ultimate responsibility for the POE?
- What role will assisted living play in the POE plan?
- How will people in need of services for dementia or mental health be cared for?
- What role does saving money have in the state's plans for the POE and for Medicaid changes, and what steps are being taken to ensure that consumers are protected? □



If you are interested in joining one of our Committees and helping us address these issues, please call us at 212-385-0355. LTCCC Committee membership is open to all Coalition members.

EPIC WORKS...

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critical decisions about whether they will protect seniors in EPIC and people with disabilities who need to be included in EPIC. We believe there are opportunities to ensure that New York's commitment to promoting access to affordable drug coverage is maintained where it now exists and realized where it doesn't. With the right kind of coordination with the Medicare Part D benefit that is seamless, New York could achieve savings with federal funds to include the disabled in EPIC and lower cost-sharing for participants.

EPIC WORKS endorsing organizations are urging our elected officials to use these six principles as a road map toward these goals. They are:

1. Coordination between EPIC and Medicare Part D plans should be seamless from the enrollee's perspective. Coordinating Part D plans should meet EPIC's goal to guarantee minimal changes for enrollees, no increased cost-sharing, continued access to EPIC's open formulary and comprehensive pharmacy network. In the event that coordination is not seamless and does not meet EPIC's goal, Medicare Part D participation should be voluntary for EPIC participants. Any auto-enrollment into Part D plans must provide the option to decline.

2. Non-elderly adults with disabilities qualifying for Social Security Disability Insurance (SSDI) should be included in the EPIC program on the same terms as seniors.

3. EPIC should lower the prices of prescription drugs by joining its purchasing power with that of other state-funded programs.

4. Savings that accrue from coordination with Medicare Part D should stay in the EPIC program and be used first to include the non-elderly SSDI disabled and to lower cost-sharing for participants.

5. A major portion of the \$34 million in transitional assistance New York is receiving should be used to provide direct grants to community based organizations for education and case management of disabled and elderly individuals seeking assistance in the transition to Medicare Part D, particularly those facing language and other barriers.

6. Dually eligible elderly and disabled Medicare/Medicaid beneficiaries should receive the same level of protections from the inadequacies of the Part D benefit as EPIC enrollees.

Written by Lani Sanjek, Acting Executive Director, NY StateWide Senior Action Council, a member of LTCCC. For more information, contact Michael Burgess at NY Statewide Senior Action Council (518) 436-1006 or swnys@aol.com, or David Wunsch at New Yorkers for Accessible Health Coverage (NYFAHC) (646) 442-4184 or nyfahc@cidny.org. For information about EPIC: 1-800-332-3742.

WHAT YOU CAN DO!

- 1. Contact your State Senator and State Assembly-member and urge them to support the EPIC WORKS principles.**
- 2. Get your organization to endorse EPIC WORKS.**

Special Action Alert...

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There is a major crisis in nursing home care in New York. Rather than being cared for, many nursing home residents are faced with outrageous, often heart-breaking conditions. These are our parents and grandparents, aunts, uncles and friends. They turn to a nursing home in need of help, but too often what they get is anguish — insufficient staff to help them walk to the bathroom, eat a nutritious meal or even to move them around in bed. As a result, unnecessary incontinence, malnourishment and painful bedsores are major problems for nursing home residents.

As a legislator you have a critical role in insuring that the state fulfills its mandate to ensure the care and safety of nursing home residents. You can do something about this situation.

We ask Assembly members to join as co-sponsors of the Nursing Home Diversion Act (NHDA), Assembly Bill #8866, which would stop nursing homes with dangerously low staffing from taking in new residents until they improve. For the letters to senators, we are ask that they introduce a companion bill.

It is critical that the state move forward and protect nursing home residents this year. You can make a difference by speaking out now. Please take a moment to make your voice heard. □

Providers Hold Conference on New York's Point of Entry Plan for Long Term Care

On November 30th, Martin Sobel, one of LTCCC's policy interns, traveled to Albany and attended a day-long conference called "New York State Seeks ANSWERS: Other States' Experiences with Point of Entry". The conference was sponsored by seven provider associations and was held to educate the providers within their associations. LTCCC attendance was made possible by an invitation from a sponsoring association and our vocal desire to be at the forefront of understanding all perspectives, issues, and concerns of a POE system.

The morning session began with keynote speaker, Virginia Dize, Associate Director, Home and Community Based Services, National Association of State Units on Aging. She presented a national perspective, stating that there is a need to consolidate administration of long term care in order to respond to consumer demands, reduce Medicaid spending, decrease nursing home use while increasing availability of home and community based services, and reorganize state and local delivery systems to be more coordinated, collaborative and efficient.

The conference continued with three people from other states describing how their systems are functioning: Krista Boston, Supervisor, Consumer Information, Assistance and Advocacy Team, Minnesota Board of Aging, Donna McDowell, Director, Bureau of Aging and Long Term Care Resources, Wisconsin Department of Health and Family Services, and Stephanie Sue Stein, Director, Milwaukee County Department on Aging.

According to Ms. McDowell, Minnesota's primary strategy is "an effective information and access system...to address changing [the] landscape for consumers." Thus, she said, program designers identified the needs of the consumers and developed a system that is accessible all the time, relevant, easy to navigate, available in varying forms - print, phone, Internet, in person - and unique, in respect to personal characteristics.

According to Ms. Stein, Wisconsin's program is a "One Stop Shop," providing information on and how to access community resources beyond the normal consumer services, both public and private. Their system is an interdisciplinary approach for assessment

and care management, centered on helping consumers solve problems - either medically or non-medically, through better system coordination. Much of the work is derived from regionalized resource centers, which reach out to the community in wellness and prevention efforts and provide case management/planning in order to better prepare for service delivery during consumers' times of crisis.

The conference later concluded with a presentation from Kathryn Kuhmerker, Deputy Commissioner, Office of Medicaid Management, NYSDOH, and Neal Lane, Acting Director, NYS Office for the Aging (SOFA). They discussed the reasons for reform, the components of a POE, and the creation of the Interim Report from the Governor's work group on Medicaid and NY ANSWERS (see previous issues of *The Monitor* for reports on these issues). They then went on to discuss a summary of 127 responses to the Request for Information (RFI) on the POE proposal and the twelve SOFA "listening sessions" held statewide, which they said were staged to facilitate stakeholder participation in the POE developments. For example, they reported that stakeholders consistently indicated the need to phase-in an unbiased, coordinated system that builds on existing efforts and provides information and assistance, education, and outreach to all. There are major concerns about the inadequate size of the workforce and the ability to maintain consumer choice when they run counter to case managers' preferences. On the other hand, they found that there was limited consensus on how the state should structure the POE program and whether the State is implementing this program with a hidden agenda of cost cutting or gate-keeping.

Attendees also learned that many providers are concerned about the ability of case managers to make unbiased assessments and referrals; that many providers would prefer extensive revision of the current regulatory system; and that they believe a POE will merely create an additional layer of bureaucracy.

The Coalition will be continuing its work on the POE with the release, early in 2005, of a full-report focusing on the consumer perspective of a POE system. □

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To write to your representative in the Assembly, address your letters to him or her at NYS Assembly, Albany, NY 12248. The general switchboard for the Assembly is 518-455-4100.

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To obtain the names of your personal state government representatives, go to The Citizen Action Center on our website:
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