

# M<sup>LTC</sup> Monitor

FALL/WINTER 2004 THE LONG TERM CARE ADVOCATES' NEWSLETTER

## Legislative Priority: The Nursing Home Diversion Act

### *Where is the outrage? Where is the anger?*

Our nursing home residents are not safe. There is not enough staff in nursing homes to care for our most vulnerable citizens. How can we let residents sit in their own waste as they wait to be taken to the bathroom? How can we let bedsores develop because there is not enough staff to turn residents or give proper skin care? How can we restrain residents because we do not have enough staff to supervise them? Eighteen percent of our residents have bedsores, five percent are physically restrained, fifty percent of people not at risk have lost control of their bowels or bladder.

We have long known that New York State nursing homes are drastically understaffed. Federal studies indicate that residents need nursing care of at least 4.1 hours of total nursing time to avoid bedsores, weight loss, and loss of bodily functions for long-term

residents. Yet, New York State's average is only 3.6 hours. Thus, half of the homes are below this average which is itself too low to keep people safe.

### *When will something be done? How long will it take?*

Just about everyone agrees that there is widespread suffering in New York's nursing homes and that staff shortages are the leading cause of poor care. Yet, year after year, our leaders in Albany fail to take steps to protect vulnerable residents. There has been a Safe Staffing bill in the legislature for several years now but it has not passed into law. The Assembly passed a bill

introduced by Health Committee Chair Richard Gottfried several years ago but the Senate bill, introduced Health Committee Chair Kemp Hannon, failed to move forward. Currently, there are safe staffing bills pending in both houses (A05490 and S02304). The Senate bill has not even made it out of committee.

Because of the continued failure in Albany to support this long term solution to the nursing home crisis, we developed a stop-gap emergency measure with Assemblyman Gottfried to do something immediately – to stem the flow of innocent people into the state's most poorly staffed nursing homes. The Nursing Home Diversion Act (NHDA) would be similar to the policy already in place for many hospital emergency rooms which divert incoming patients to other

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### Legislation

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## Nursing Home Diversion Act...

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hospitals when they don't have enough staff to care for additional patients. The NHDA would require nursing homes with dangerously inadequate staffing (below 3 hours of care for each resident per day) to divert incoming people to other local homes until they can achieve a safer level. For family members and others concerned about resident safety, it is unconscionable to imagine allowing people to enter a nursing home with this low level – it is more like a warehouse than a place where people can get care (much less call home).

The Coalition worked hard on this bill with Assembly Health Committee Chair Richard Gottfried. Thanks to all of you who responded to our action alerts this year asking people to email, fax or write their leaders to support this important bill. The NHDA (Assembly bill #8866) has gained significant momentum in the Assembly. It has grown from one sponsor to 27. However, while the Assembly focuses on this issue which many people believe is an emergency, the Senate sits by while nursing home residents suffer.

Now is the time to make sure that our legislators understand how bad it is in nursing homes today. The Senate must introduce and pass this bill now. Do we wait for the average to drop to 2 hours a day; do we wait for deaths to rise or do we do something now? You must let your senators and Governor Pataki know that nursing home residents should not be “dumped” into facilities which cannot care for them. Elderly people cannot be warehoused in places that do not maintain sufficient staff to safely care for them.

The Coalition plans to focus this coming session on getting the word out, educating the Senators and Governor on the impact of severely low staffing on vulnerable residents. We want them to be as outraged as we are about the impact of severely low staffing on vulnerable residents. Often legislators understand this once they have personal knowledge of nursing homes with family members. We cannot wait for this to happen to every legislator in New York.



**SPEAK OUT:** Visit our website, [www.ltccc.org](http://www.ltccc.org), and go to our Citizen Action Center and send a free fax, email or letter supporting the Nursing Home Diversion Act. The action is called “Support the Nursing Home Diversion Act.” Or see the back cover of this newsletter for addresses and phone numbers of the Albany leadership.

**TELL YOUR STORY:** The Coalition has a “Tell My Story” campaign in which we collect the personal stories of people who have had bad experiences with low staffing in nursing homes. People can tell their stories anonymously or they can use their name or even include a picture. These stories are very important — they help us to put a “human face” on the crisis with our state leaders and with reporters. Visit our website, [www.ltccc.org](http://www.ltccc.org), and click on the middle button (“Take Action”) to go to the page where you can download the *Tell My Story* form. Or call Barbara at (212) 385-0355 to receive a copy by mail. □

## LTCCC Takes Steps to Participate in Development of POE/Access to Care Plans

As reported in the last issue of *The Monitor*, earlier this year the Governor's Health Care Reform Working Group released their Interim Report, which included a major proposal to change the delivery of long term care in New York State. Through a plan called NY ANSWERS, the State hopes to implement a single point of entry (POE) for everyone who needs long term care.

The Coalition would be happy to see a more consumer friendly and easy to use system for long term care. Currently there is much confusion, and people often do not know where to go for help. However, we are very concerned that the system actually developed will be focused on saving money and

will not help consumers find the best care for themselves as individuals.

Since the State issued its report, LTCCC has been working to ensure that consumer interests are considered in the plan's development and that consumers are protected. Those efforts included researching other states with a POE system, hosting a special presentation at our July Coalition meeting by Sue Kelly - Director of the Division of Medicaid and Children's Health, Centers for Medicare and Medicaid Services (CMS), New York Region 2, and the forming of a new committee to address the POE and access to care.

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# New York Legislature Passes Assisted Living Legislation

After months of intense negotiation by the Long Term Care Coalition and its partner organizations, the New York Assembly and Senate unanimously passed effective assisted living licensure legislation in August. LTCCC played a vital role in ensuring that the bill (A11820/S7748) provides valuable and sensible consumer protection, rights and regulation. As of the newsletter's publication date, the bill awaits the signature of Governor Pataki to become the law of the state.

As readers of *The Monitor* know, LTCCC has been advocating for assisted living legislation for several years. Last year, the Assembly, Senate & Governor appeared to be close to agreeing on a bill, but negotiations fell through at the last moment. In the last few months of this past session, there again was a significant amount of discussion surrounding possible legislation. Several proposals were introduced including those by Governor Pataki and Assemblyperson Englebright.

At the end of June, the Assembly passed an assisted living bill proposed by Assemblyperson Englebright with unanimous, bipartisan support. The Senate failed to take action on this bill. As the legislative session was nearing its end a new draft of the bill was negotiated. The Coalition played a key role in these negotiations, working with all sides to ensure that consumers are protected and also galvanizing consumers to speak out and let state leaders know that New York's citizens wanted assisted living protections this year. Finally, a good bill was introduced in both the Assembly and the Senate for a successful vote.

We strongly believe that this bill would not have passed had there not been active support from Coalition members and supporters. Through the citizen action center, phone calls, emails and letters, our grassroots efforts sent a clear message to the leaders in Albany that strong assisted living legislation needed to happen now. Thank you to everyone who sent a

message to their political leaders.

The assisted living licensure legislation includes many of the provisions LTCCC has been fighting for including a clear definition of assisted living that details necessary services, special certification for "aging in place" and cognitive impairments and strong disclosure requirements that enable consumers to make informed decisions.

Perhaps the most striking feature of the bill is the stipulation that all facilities that wish to function and market themselves as assisted living residences must first become licensed adult home or enriched housing facilities before they can apply for an assisted living license.

The next step for LTCCC will be ensuring that the new consumer protections are strongly implemented and followed.

The bill in its entirety can be accessed at [www.assembly.state.ny.us](http://www.assembly.state.ny.us) (search for Assembly bill number 11820. A full summary of the bill is on our website, [www.ltccc.org](http://www.ltccc.org)).

## Key points from the Assisted Living Licensure Bill

1. The bill clearly defines assisted living: "The term "assisted living" and "assisted living residence" means an entity which provides or arranges for housing, on-site monitoring, and personal care services and/or home care services (either directly or indirectly), in a home-like setting to five or more adult residents unrelated to the assisted living provider." Assisted living residences must supply daily food service, twenty-four hour on-site monitoring, case management services; and individualized service plans for all residents.

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Shay Bergin, Senior aide to Assemblyman Richard Gottfried, chair of the Health Committee, speaks to the full coalition on September 20, 2004.



# Assisted Living Legislation...

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2. Providers who want to become assisted living residences must apply to DOH for licensure and approval. As part of this approval process, DOH is required to solicit and consider public comment on its webpage.

3. Assisted living residences that choose to offer a higher level of care (permit “aging-in”) must apply for an “enhanced assisted living certificate.”

4. Assisted living residences that choose to market special services for people with cognitive disorders will be required to obtain a “special needs assisted living certificate” from the Department of Health (DOH).

5. The fees, along with revenue generated by monetary penalties for violations of the law and regulations, will be deposited into a special fund that will pay for the costs associated with the regulatory oversight of assisted living residences. \$500,000 will go to support the work of the Long Term Care Ombudsmen Program.

6. To admit someone into an assisted living residence, the legislation requires a pre-admission evaluation to determine if the provider can meet the resident’s needs. People who need 24-hour skilled nursing care cannot be admitted to an assisted living residence. However, residents of enhanced assisted living residences may be permitted to remain in the facility once they require 24 hour skilled nursing care under specified conditions.

7. The admission process includes executing an admission agreement with residents that includes the terms and conditions of the residency. Providers will also have to disclose certain information about the facility along with its marketing materials and a consumer information guide to anyone who expresses an interest in living in the facility.

8. Upon admission, an individualized service plan (ISP) must be developed for each resident and must take

into account the medical, nutritional, rehabilitation, functional, cognitive and other needs of the resident. The ISP must be updated as necessary to reflect changing resident needs, but no less than every six months.

9. The bill includes a section on resident rights similar to those currently in effect for residents of licensed adult homes.

**“We strongly believe that this bill would not have passed had there not been active support from Coalition members and supporters.”**

## Chapter Amendments

The Governor has agreed to consider a “chapter amendment” to consider concerns raised by a few organizations. LTCCC has joined with the Coalition for the Homeless, Alzheimer’s Association, NY StateWide Senior Action

Council, Coalition of Institutionalized Aged and Disabled, Schuyler Center for Analysis and Advocacy, and New York Association of Psychiatric Rehabilitation Services to ask for the following to be considered:

- **Special needs plans for mentally ill residents should not be allowed for assisted living operators, and the provisions for special needs plans for those with cognitive impairments or dementia must be strengthened to include those facilities serving this population, not just those that market themselves as doing so.**
- **If the dementia population changes in any way, plans must be updated.**
- **The legislation should reference health care practitioners, not just physicians.**
- **In order to deal with the issue of publicly traded corporations being licensed as adult homes before becoming licensed as assisted living residences, language related to “representative governance” developed by the Public Health Council and the DOH for publicly traded corporations operating health care services must be included.**

Check our website for any updates on these chapter amendments. □



# Legislative Update: Adult Home Reform

The legislative session ended with disappointment for adult home residents. The Legislature's plan to spend \$10 million, the amount budgeted in the Executive Budget for adult home reform, was vetoed by the Governor at the end of this legislative session.

The Legislature's plan included \$3 million dollars for a personal needs allowance increase for adult home residents and a Supplemental Security Income (SSI) adult home operator rate increase. Residents would have seen an increase of \$30 to their monthly personal needs allowance: \$138 per month effective January 1, 2005 and \$157 per month effective January 1, 2006. Currently, the amount is \$127. Adult homes and enriched housing programs would have been newly categorized as "enhanced residential care" and received \$31.70 per day downstate and \$30.70 per day upstate effective January 1, 2005; and \$35.06 per day everywhere effective January 1, 2006. Currently the amount is about \$28 a day.

The Legislature would have also provided \$3.5 million for Quality Incentive or QUIP payments, a quality enhancement fund for adult home operators; \$3 million for additional new case management/peer specialist programs; and \$500,000 to fund a Housing Assistance Office for Adult Home Residents.

## **Legislation that did pass will:**

- Require Resident Council approval of the operator's proposed QUIP expenditure plan. It will also be harder for the Department of Health (DOH) to deny any home QUIP funds.
- Prohibit hospitals, correction, parole, OMRDD, OMH and OASAS facilities and local social services districts from referring people to homes on the "Do Not Refer List." This is a list of homes developed by DOH that have received notice from DOH of

enforcement action based on endangerment of resident health or safety. It will also allow the possibility of removal from the Do Not Refer List if the operator corrects violations.

- Require DOH to list homes facing enforcement action and on the Do Not Refer list on their web site.
- Establish a mechanism for voluntarily placing adult homes in receivership based on agreements between the DOH and an operator of an adult home.
- Protect against the arbitrary discharge of an adult home resident during receivership.

**“Adult home residents are very disappointed that they got so close but did not achieve one of their major goals – a personal needs allowance increase.”**

- Establish statutory requirements for temperature controls and require that at least one common room in an adult home be air conditioned.

- Prohibit an operator of an adult home with a suspended or revoked license from applying to be an operator of another facility.

- Create the Adult Home Quality of Care Enhancement Fund to be funded with fines imposed against adult homes in violation of New York State regulations. Funds will be "disbursed by DOH to promote programs to improve the quality of care in adult homes."

Adult home residents are very disappointed that they got so close but did not achieve one of their major goals – a personal needs allowance increase. They and their allies in the consumer advocacy community are also disappointed in not achieving other important priorities this year, including a resident clothing allowance, the establishment of a State Office of Mental Health housing waiting list, and Public Health Council review of operators.

*Written by Geoff Lieberman, Executive Director of the Coalition of Institutionalized Aged and Disabled, and Vice President of LTCCC. □*



# ENFORCEMENT ACTIONS AGAINST NURSING HOMES<sup>1</sup>

6-15-04 — 9-15-04

## The State Fined 21 Nursing Homes

NAME OF HOME	LOCATION	DATE OF SURVEY	AMOUNT
Adventist NH	Livingston	02/27/03	1,000
Beechwood NH	Getzville	07/03/03	1,000
Community Gen. Hosp.	Syracuse	06/11/01	4,000
Daughters of Sarah NH	Albany	03/12/03, 04/29/03, 07/10/03	3,000
Dumont Masonic Home	New Rochelle	12/27/02, 01/07/03	3,000
Franklin Hosp. Medical Center NH	Valley Stream	01/18/02	1,000
Grandell Rehab & Nursing Center	Long Beach	11/29/01	3,000
Hornell Gardens	Moravia	05/29/03	2,000
Horizon Care Ctr.	Arverne	06/11/03	3,000
John J. Foley SNF	Yaphank	04/06/01	2,000
Mayfair Care Ctr.	Hempstead	03/22/02, 04/25/02	4,000
Medford MultiCare Ctr.	Medford	04/15/03	6,000
Medina Memorial Hosp. SNF	Medina	10/23/03	2,000
Mercy of Northern NY	Watertown	11/25/02	1,000
Midway NH	Maspeth	09/20/01	2,000
Resurrection NH	Castleton-On-Hudson	10/22/02	6,000
St. Luke's Presbyterian Nursing Ctr.	Buffalo	03/02/01, 08/09/01, 09/16/03	7,000
Stonehedge NH, Chittenango	Rome	10/11/02	4,000
Teresian House NH Co.	Albany	11/15/02, 01/09/03	8,000
Unity Living Ctr	Rochester	02/21/03	1,000
Wesley Gardens NH	Rochester	06/27/03	2,000

<sup>1</sup>As reported by the Department of 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.

## The State Took Other Actions at 6 Nursing Homes

In addition to the actions listed below, the following nursing homes might be fined at a later date. 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), or to have repeated deficiencies that have caused isolated resident harm (G), it is noted in the third column. Double G - Have received G's in two consecutive surveys.

NAME OF HOME	LOCATION	IJ, SQC or G	SURVEY DATE	ACTIONS <sup>1</sup>
Episcopal Church Home	Rochester	IJ/SQC	09/10/04	POC, State Monitor, DOPNA
Fieldston Lodge	Bronx	IJ/SQC	08/25/04	POC, In Service, State Monitor, DOPNA
Ocean Promenade Park	Rockaway	IJ/SQC	06/21/04	POC, In Service, State Monitor, DOPNA
River Mede Care Ctr.	Binghamton	IJ/SQC	07/02/04	POC, In Service, State Monitor, DOPNA
Rosewood Heights	Syracuse	Double G	07/29/04	POC, In Service, DOPNA
Rutland NH	Brooklyn	Double G	06/25/04	POC, In Service, DOPNA

<sup>1</sup>**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.

## Residents Have the Answers: Improving Quality of Life in Long Term Care

The Long Term Care Community Coalition and the Coalition of Institutionalized Aged and Disabled have developed a method of assessing quality of life by talking to residents. The package, which is available from a number of distributors, includes a 33-minute video, a complete training and resource guide for nursing home staff and a PC computer diskette with questionnaire templates that can be customized for use in different facilities.

Let the nursing homes you visit know about this package and urge them to use it. The following companies are authorized to sell the package:



(1) American Health Care Association, 800-321-0343, <http://www.ahca.org/store/index.html> (the product id number is 6755, members' price is \$75.00; non-members' price is \$139.00);

(2) Springer Publishing Company, 877- 687-7476; [www.springerpub.com](http://www.springerpub.com) (the video costs \$129.00 - outside US \$144.00); and (3) Terra Nova Films, Inc, [tnf@terranova.org](mailto:tnf@terranova.org), 800-779-8491, [http://www.terranova.org/Title.aspx? CatSort=249](http://www.terranova.org/Title.aspx?CatSort=249) (the rental fee is \$45.00 and the purchase price is \$139.00).□

## Managed Long Term Care Consumer Guide Finally Released!

LTCCC's Managed Long Term Care Subcommittee worked with the Department of Health and the State Office for the Aging for a number of years developing educational materials for people who are in, or are considering enrollment in, managed long-term care plans. The goal of the materials is to give people the knowledge they need about these plans and to make sure they understand their rights under such plans. The Subcommittee wrote numerous drafts of the materials, helped develop questionnaires for the pilot testing and helped identify individuals for the pilot

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# No Excess Income Spend-Down for Medicaid Home Care

As a result of a New York State fair-hearing decision, persons of any age with community Medicaid services, including home care, and adult-day care services and prescription drugs, are now able to use virtually all of their income to pay for their living expenses by participating in a pooled-income trust rather than contributing their “excess” income to Medicaid. An individual need not contribute his “excess” income to the Medicaid program in order to either become eligible or maintain his eligibility for Medicaid community services.

Established by a non-profit organization, the pooled-income trust receives the beneficiary’s “excess” income and redistributes it on his behalf as directed by the beneficiary or his representative. Although advocates believed that Federal law already permitted this, it was never tested until recently.

## ***The Program Works as Follows...***

Suppose Mr. Smith has a monthly income of \$1,679 in Social Security and pension income and is utilizing Medicaid home care. Under Medicaid guidelines he is only allowed to keep \$679 of that income. His “excess” or monthly surplus is \$1,000 ( $\$1,679 - \$679 = \$1,000$ ). He has to send a check each month for that amount to his health-care provider as a contribution toward the cost of his care.

Now, if Mr. Smith joins the pooled-income trust his \$1,000 check will be sent to the trust office instead of the health-care provider. It will be used to help pay his bills rather than to offset the cost of his care. He will keep \$679 as he does now to pay expenses. Using the \$1000 of “excess” income, Mr. Smith’s additional expenses (for rent, food, utilities, clothing, etc.) will be paid by the trust according to instructions from Mr. Smith or his representative, and his Medicaid services will remain in effect.

All individuals who are disabled as defined under the Social Security law are eligible to join the trust.

(Persons of any age who are eligible for Medicaid home-care or adult-day-care services are presumed disabled and therefore qualified to join the trust.) In order for a person to participate in the trust, an agree-

ment between the beneficiary and the trust must be completed under which the individual enrolls in and establishes an account under the community trust. The agreement must be signed by the trustee and the disabled individual (who must have capacity), or, if an individual does not have capacity, by a parent, grandparent, guardian or a person acting under a durable power of attorney, or it must be approved by the court.

To initiate the process of conserving the “excess,” the individual beneficiary should deposit into his separate trust account the equivalent of two months’ excess income - one month as deposit and the other as working capital. There is a nominal service fee charged by the trust and determined on a sliding scale, ranging from approximately \$35 to \$150 per month.

Upon the death of the beneficiary, the funds in the account remain with the trust to benefit other disabled individuals. Note that the amount, if any, left in the account is likely to be negligible given the individual’s need to utilize the funds each month.

Non-profit organizations sponsoring pooled-income community trusts include NYSARC, Delmar, NY; AHRC (Association to Help Retarded Children), Manhattan; and the Lifetime Care Foundation for the Jewish Disabled (OHDL), Brooklyn. The Department of Social Services must make sure you are enrolled in a pooled-income trust before it agrees not to require you to contribute your “excess” income to Medicaid.

Before proceeding with the pooled-income trust, individuals and their families are strongly encouraged to consult with an attorney who has knowledge of and experience in planning for long-term-care needs. □

*Written by Martin Petroff, Esq., Petroff & Lamson and LTCCC Board Member.*

**“An individual need not contribute his “excess” income to the Medicaid program in order to either become eligible or maintain his eligibility for Medicaid community services.”**



# New Law Adds Protections For Nursing Home Family Councils

Governor Pataki signed into law a bill that empowers and protects Family Councils at New York nursing homes. The law defines the rights of Family Councils, prohibits nursing homes from preventing their formation and operation, and mandates that nursing homes designate a specific staff person to respond to council complaints and recommendations.

The new law's added protections and support for Family Councils will make it possible for their numbers and effectiveness to increase, benefiting nursing home residents as well as the nursing homes themselves.

Many well run nursing homes understand the value of Family Councils and have encouraged them, but too often administrators try to undermine and even retaliate against residents and their families and friends for Family Council activity. Family Councils are a vital component in any facility that wishes to provide resident centered care.

There are many ways in which Family Councils enhance resident quality of life and improve the care residents receive. They can monitor and make recommendations about the care provided by individual homes and bring resident complaints and concerns to the attention of nursing home staff. Family Councils are an effective way to bring about change in nursing homes; many voices are stronger than one.

## FAMILY COUNCIL BILL FACTS

Existing Federal and New York State law and regulations allow family and friends the right to meet together with other families and residents in the facility. They also require the "facility to listen to the views of this group and act upon their grievances and recommendations."

The new legislation, New York State A.00793/S.07582, prohibits nursing homes from interfering with family councils and requires facilities to support councils in several new ways. Under it, facilities will be required to:

- Make bulletin board space available for family council use

- Notify relatives of newly admitted residents about the family council
- Mail meeting and contact information, at least quarterly

- Designate a specific staff person to respond in writing, within a fixed time frame, to council requests and concerns.

**“Family Councils enhance resident quality of life and improve the care residents receive.”**

In addition, the bill recognizes the right of a family council to meet privately, to invite outsiders and to meet at least monthly.

Summaries of the bill, the bill text, and the bill's legislative history can be found at <http://assembly.state.ny.us/leg/?bn=A00793>.

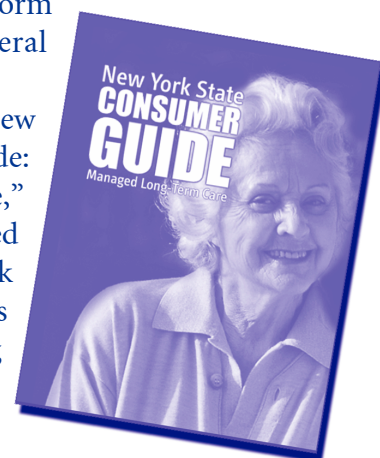
*Written by Friends and Relatives of Institutionalized Aged (FRIA) staff. FRIA, a member of the Long Term Care Community Coalition, operates the "Family Council Project," which provides assistance to persons who wish to create and maintain councils. For additional information, visit the "Family Councils" page at FRIA's web site, [www.fria.org](http://www.fria.org). □*

## Guide Finally Released!...

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testing. We are very proud to have contributed significantly to this effort to inform consumers and the general public.

The finished product, "New York State Consumer Guide: Managed Long Term Care," can be seen and downloaded for free from the New York Department of Health's website at the following link: [http://www.health.state.ny.us/nysdoh/macare/mltc/pdf/mltc\\_cons\\_guide.pdf](http://www.health.state.ny.us/nysdoh/macare/mltc/pdf/mltc_cons_guide.pdf). Or you can find the link on the Managed Long Term Care page of our website, [www.ltccc.org](http://www.ltccc.org), along with other news and resources on long term care.



# LTCCC Takes Steps...

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## Background

In general, a POE system for long term care is defined as one place for information and referrals for care, one place to find out about and apply for services and one place to evaluate and provide recommendations of services. Thus far, we have identified at least 18 states – including New Jersey, Massachusetts, Maine and Maryland – with such a system. Different places refer to a POE program differently: a POE may be referred to as a single entry point, aging single access point, options for long term care or single point of contact system. States have created their systems for various reasons, but a familiar theme we identified was development as part of an effort to respond to the U.S. Supreme Court's Olmstead decision, which requires that states provide long term care in the least restrictive setting possible for each individual. Additionally, the growth in the number of seniors, a lack of knowledge about services among seniors, a lack of assessment consistency and sharing, and a lack of service coordination are reasons given for why states considered a POE. One of the major motives for New York's plan seems to be Medicaid cost containment.

## Coalition Activities

LTCCC intends to be actively involved in the development of this system. To monitor the POE and present a strong consumer voice as it develops, the Coalition has formed a new Committee on Access to Care/POE. The Committee consists of many leaders in the aging, disabled and healthcare communities, including Alzheimer's Association, United Hospital Fund, Disabled in Action, NY State Nurses Association, Paraprofessional Healthcare Institute, Center for Independence of the Disabled, Friends and Relatives of Institutionalized Aged, Coalition of Institutionalized Aged & Disabled and Brooklyn Wide Interagency Council on Aging. These groups, through the Committee, will be spearheading the Coalition's work on this issue, assessing developments, engaging policy makers, presenting a strong and unified consumer response and making sure that the media and general public are educated about POE developments and their impact on long term care consumers.

LTCCC is in the process of conducting research analyzing other states' experiences with single point of entry system, including assessing states' goals, regulations and impact on consumer care. This analysis

will be followed by the distribution of questionnaires nationwide to consumer advocates and ombudsmen in order to further understand states' experiences of POE implementation from a consumer perspective. In addition the Coalition developed a questionnaire for people to bring with them to "listening" sessions conducted by the state to learn about pertinent issues from the state and report them back to us. LTCCC will use these data as a basis for the POE Committee's recommendations and as the foundation of a report which we will use to educate the political leaders, media, organizations and interested citizens in New York.

## Medicaid and the POE

When Sue Kelly attended our Coalition meeting she discussed how the Medicaid system is an integral part of long term care delivery. It pays the medical bills of people who have low income, cannot afford medical insurance, and meet other eligibility requirements decided by the states. Certain services, such as nursing home care and inpatient/outpatient hospital services are mandated by the federal government, while other optional services, such as prescription drugs are at the discretion of each state. Currently, Medicaid pays for one half of nursing home care in the United States. Long term care spending in New York State accounts for the largest segment of the State's Medicaid expenditures. Both the federal government and the states split the cost of Medicaid expenditures, with the federal government paying about 50% in New York State.

Interestingly, CMS may play a role in State adoption of a POE if the State applies for a Medicaid waiver. A Medicaid waiver can be issued either to allow the State to amend eligibility standards; to remove the ability for enrollees to choose their provider; or to provide services that normally are not available. Additionally, states have used Medicaid waivers to get more federal funds and grants. However, a POE system can be instituted without a waiver as long as it does not alter present long term care services and coverage. If it does, a waiver must be approved by the federal government. LTCCC will be monitoring any movement on this issue. If a Medicaid waiver is applied for, we will participate vigorously in its development.

In the future, the LTCCC and its POE/Access to Care Committee will both be proactive by presenting recommendations from our data and our POE Committee and be reactive by continuing to monitor New York's plans and address issues as they develop. Be sure to read future issues of this newsletter for updates, or visit the new Access to Care page on our website, [www.ltccc.org](http://www.ltccc.org). □

# You Can Help Us Make A Difference: Please Donate Today

Though we only have a small staff of three people, LTCCC is able to accomplish a lot to improve long-term care in New York State. However, we need your help to continue. Among the accomplishments that your past support has brought about:

- We were instrumental in the passage of the assisted living licensure bill (see “New York Legislature Passes Assisted Living Legislation” in this edition of *The Monitor*). All assisted living residences must now be licensed! Your donations enabled us to devote time and resources to this important effort.

- We wrote and distributed a number of reports, all of which are available for free from our website, on the true costs of low staffing in nursing homes, nursing home working conditions, and nurse aide training and screening. All of these reports have helped in our fight for better care. Your donations gave us the resources to conduct these important studies and offer them for free.

- We developed new ways of arming our members and other citizens with the information they need to advocate for improved care. Your donations made possible the following services:

- ♦ Our free monthly Long Term Care (LTC) E-Newsletter gives people news about specific long-term care issues affecting them. It also contains links to websites of interest to the elderly and other long-term care consumers. It features a “Spotlight on Advocacy” with a targeted action that people can take each month on a relevant nursing home, assisted living or other long-term care issue.

- ♦ Our on-line Citizen Action Center, which is free, is readily accessible on our website, and is easy to use. This Center informs our members, New York long term care consumers and other citizens about important issues that they can speak out on, including nursing home staffing, access to mental health care in nursing homes, nurse aide training, and the attorney general’s efforts to protect nursing home residents.



- ♦ We have continued to publish our free newsletter every three months.

- ♦ We have continued to hold membership meetings every two months, for our

members to meet and listen to speakers on important issues.

- ♦ Our directors have made numerous presentations to consumer and provider groups on long term care issues.

There are many other things we do: meet with Federal staff overseeing nursing homes, meet with legislators to educate them on issues affecting the elderly and disabled, governor’s staff, department of health, etc., staff coalition subcommittee meetings, etc.

Your support is needed so that we can continue to have such success and offer these services. Please consider donating (tax-deductible) to help support our work. All money we receive goes directly to our programs to improve care for some of our most vulnerable citizens. Please send a check to: LTCCC, 242 West 30th Street, Suite 306, New York, NY 10001 OR donate on-line by going to our website ([www.ltccc.org](http://www.ltccc.org)) and clicking on the donate button. With your help, we will be able to list many more actions next year. □

## Help LTCCC Assess Nursing Home Survey System

LTCCC has been awarded a grant by the New York Community Trust to examine the effectiveness of the New York State Department of Health’s nursing home surveillance system. In addition to analyzing data from the federal government related to deficiencies written, resident characteristics and staffing, LTCCC will be gathering information from consumers who have had experience with the State’s survey or complaint system.

If you have had experiences with the Department of Health in nursing homes and would like to be involved in this project, please call (212-385-0355), write (242 West 30th Street, Suite 306, NY 10001) or e-mail ([barbara@ltccc.org](mailto:barbara@ltccc.org)) us with your contact information and we will get in touch with you. You will be able to keep information about your identity confidential. □

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#### New York State Assembly:

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.

In addition to your personal representative, it is important that the following leaders hear from you:

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#### New York State Senate:

To write to your Senator, address your letters to him or her at NYS Senate, Albany, NY 12247. The general switchboard for the Senate is 518-455-2800.

In addition to your personal senator, it is important that the following leaders hear from you: Senator Joseph Bruno

Majority Leader  
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Senator Kemp Hannon  
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To obtain the names of your personal state government representatives, go to The Citizen Action Center on our website: [www.ltccc.org](http://www.ltccc.org).

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