

**TESTIMONY OF FRIENDS AND RELATIVES OF INSTITUTIONALIZED AGED
(FRIA)**

ON THE LONG TERM CARE COMPACT

AT A PUBLIC HEARING HELD BEFORE

THE NEW YORK STATE ASSEMBLY

COMMITTEES ON AGING, HEALTH, AND INSURANCE

December 4, 2006

FRIA thanks the Committee for allowing it to submit these written comments regarding A.10634A, which seeks to establish the New York State Compact for Long Term Care.

Since 1976, FRIA has been NYS's unique consumer resource for free information and assistance on long term care issues, with a special focus on nursing home care. FRIA has played a pivotal role in reforming the industry since its inception. In addition, FRIA provides direct services to seniors and their informal caregivers, working to improve individual problems with long term care as well as positively impact the state system generally. FRIA's services include:

- Free telephone bilingual Helpline service that assists over 1,000 callers each year on a wide array of long term care concerns,
- Organizing, assistance and support for over 60 NYS Family Councils attendant to nursing homes, representing over 20,000 nursing home residents,
- Caregiver Advocacy Center that provides information and interventions on resident rights, family rights, and care complaints, and,
- Community education and outreach that educates seniors and their families on NYS's long term care system, reaching over 1,000 community members in 2006 alone, not counting media appearances.

It is our important grassroots, individual consumer work that informs our policy insights and brings us to submit these comments on A. 10634A.

FRIA's consumers are largely low and moderate income individuals whose lives have been financially challenged by the cost of health care and long term care housing needs. The current long term care system in this state, and others, operates on the expectation that its citizens become impoverished as a condition to accessing publicly supported long term health care. The current system also accepts a lesser level of quality care for those on government support- causing untold anguish, despair and saddened aging by not adequately addressing the real costs of good quality care and by not enforcing existing laws and regulations.

We submit these comments with the overarching purpose of urgently pressing these Committees for a more comprehensive approach to long term care than is offered by this legislation or any effort we have seen to date. Specifically, while we recognize the urgency of the financial dilemmas posed by Medicaid budgets we must caution that conversation about costs must be balanced, and not prioritized over,

conversations about care quality. All too often, the financial piece of the long term care system is the main topic of public debate, while the elderly and disabled linger in inferior care systems to sadly live out their days, unwittingly facilitated by taxpayers.

And, all too often, the Medicaid budget solutions addressed by the government are directed to eliminating consumer access rather than reviewing and challenging provider reimbursements -which were laid bare in a series of investigative reporting articles in the New York Times last year. Vastly more money could be saved in government coffers if the state were to focus on this side of the equation as much as they focus on limiting consumer supports.

As to the Compact, FRIA welcomes and congratulates the authors of the Compact for undertaking the enormous task of analyzing the current system and developing an innovative and realistic approach to balancing interests. We also deeply appreciate their leadership in moving the conversation forward on these very key issues. However, we feel more time is needed to understand the changing landscape of long term care, the details of the Compact, and the impact the Compact will have on the changed system of the future. FRIA believes it is premature at this time to endorse any proposal regarding the future of long term care. Much will be happening in this area over the next year. The Commission on Health Care Facilities in the 21st Century just issued its report which will be reviewed, the state will be creating work groups to look at restructuring the long term care system including proposals integrating a single point of entry and the F-SHRP mandates, Medicaid eligibility rules continue to be discussed, and more- all dictate against a piecemeal approach to this issue. Instead, we have called on the state to develop a comprehensive plan for long term care that will integrate all of the events just mentioned including consideration of the Compact, bring stakeholders especially consumers into the dialogue, and fashion a 'fresh' system for the 21st century

Philosophically, we also question the establishment of a two-tier long term care system beyond the private pay opportunities that the affluent have today. We must wonder whether it is good policy for the state to favor economically comfortable classes of individuals to assure long term care, on the slim hope that they will pay into the pledge amount according to their full abilities. There is little to suggest that the very asset transfers that the state is currently concerned about will not take place to reduce the 'pledge amount' in the program. And, the low income families would benefit very little, if at all, from the Compact and would be left to fend for themselves in bearing the brunt of future Medicaid program cutbacks.

Other questions/concerns that we have about the compact specifically include:

FINANCIAL: FRIA supports the principle of personal responsibility for those able to pay. However, many myths and unproven beliefs exist about the magnitude of asset transfers that have resulted in the adoption of new eligibility rules that only serve to unduly burden those who can not afford long term care privately. We are not unmindful of the burgeoning dollars that will need to be committed in the future as baby boomers tap into the program. We are simply unprepared to say at this time that the Compact represents the best option for New York State. Notable alternative suggestions for long term care financing include creating a new Medicare Part that individuals would pay into during the course of their lives to help defray the government's share of costs. Another approach is to create a core of long term care

services that the government guarantees and then individuals may supplement these services privately. And, we remain interested in managed long term care program proposals, particularly if added consumer protections and choices can be applied. Above all, under all of these proposals, and especially in New York City, the cost (and availability) of accessible housing is such a critical barrier to staying in a community setting that it must be addressed head-on if any long term care financing design is to be meaningful.

ADMINISTRATIVE: More detail about the role of the administrative manager (PME) is needed to ensure that this role is not a 'gatekeeper' but an impartial representative working for equal access and fairness in the administration of the program. We urge that opportunities for appeal and hearing be more detailed, and support advocacy assistance, to assure that individuals who have spent down most of their money are not forced to accept an unfair ruling simply because they have no money left to retain an attorney to fight for their rights and entitlements. This may be especially important when a determination is made about a consumer who is physically or mentally unable to advocate for him/herself.

We also have questions about the timing, ease of administration and service access that the program requires, especially where an individual may have failing mental capacity or spent down their funds and need to transfer to Medicaid. Who will assist in this process and how can we ensure that services will be seamlessly provided while the administrative details are ironed out.

QUALITY OF CARE: It is understood that the Compact was not intended to be a monitor of the quality of care provided. However, the very nature of controlling payment for services *a priori* transforms the compact administrator's position into an oversight role. What happens if services are alleged to be inferior? Who will dispute charges for those with failing mental capacity? If bills go directly to the PME how will it be certain that those services were in fact provided?

The Compact offers an important new principle to be preserved in whatever future long term care system is developed: the recognition that, after toiling a lifetime, we should not force our most vulnerable citizens to suffer the indignity and humiliation of becoming impoverished in order to financially manage the debilitating and painful human processes that await many of us as we age. This Compact launched a sorely-needed dialogue that moves us away from this terrible, government-enforced result, and on that point alone, its provisions offer us a useful model.

Thank you for the opportunity to present our views. We are pleased to answer your questions or assist in any way we can as the Committees continue to review this topic.

Respectfully submitted,

Amy Paul, Executive Director

