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COMMITTEE ON LEGAL PROBLEMS OF THE AGING
REPORT ON PROPOSED NEW YORK STATE 2009 EXECUTIVE BUDGET

The mission of the Legal Problems of the Aging Committee of the New York City Bar Association has for many years been devoted to enhancing the lives of New York's senior citizens, in general and, more particularly, to the most vulnerable of the elderly due to reduced financial means or severe disabilities. The committee primarily fulfills this mission by focusing on substantive law that affects New York's elderly through educating the public and working with elected officials to comment on proposed legislation and/or suggest enhancements. In this report, the Committee respectfully expresses its concerns regarding certain proposed budget changes that we believe would have a drastic adverse impact on some of New York's most vulnerable citizens. Additionally, in some cases, as stated below, the Committee believes the proposals would potentially violate existing law.

1. Pooled Trust Remainders at Death of Person with Disabilities

In 1993, Congress created special supplemental needs Trusts to allow non-profit organizations that are directly involved in providing services to persons with disabilities the ability to establish and manage "pooled trusts" for such individuals. Because all the Trust accounts are pooled, there are lower transactional costs in establishing a Trust account. As such, New Yorkers with lesser means have been able to utilize a vehicle that historically was reserved for only the wealthy- a Trust account. Equally important, partnering with non-profits has the added benefit of transferring to the non-profit sector certain services that otherwise would have to be provided by the governmental sector, thereby reducing costs to the state.

The Executive Budget proposes that the Trust may only retain 10% of the Trust remainder at a beneficiary's death and the balance must go to the State to recoup the Medicaid services provided for such Trust beneficiary. The Committee opposes this proposal. We believe it is legally invalid and that it would increase costs to the state, profoundly affect the viability of these pooled trusts in the future and force many disabled New Yorkers to leave their homes and be institutionalized.

First, this proposal appears to violate Federal law. 42 USC Section 1396p (c)(a) mandates that the State Medicaid program may only recoup the amount that would not stay in the Trust at a beneficiary's death but would have otherwise passed to other beneficiaries. To the extent that assets remain in the Trust at a beneficiary's death, Medicaid has no right of reimbursement. As Medicaid is a joint Federal/State program, New York cannot impose this more restrictive requirement. Furthermore, we believe this additional restriction on eligibility may preclude New York's receipt of stimulus funds pursuant to Section 5001 (f) of the American Recovery and Reinvestment Act of 2009 as the "eligibility standards, methodologies or procedures under its state plan" would be more restrictive than they were on July 1, 2008.

This additional burden would also hamper the ability of the non-profits to continue this valuable program. Currently, the Trust program costs are not met by the Trust's administrative fees. Accordingly, the Trust's loss of the remainder funds will require enhanced administrative fees for the beneficiaries who can least afford the cost. Moreover, it will most likely result in some Trusts not being able to continue to

operate. This will further burden the State's fiscal budget because the non-profits will no longer be offsetting some of the costs.

Worse, many individuals who would lose access to those trusts will be compelled to leave their homes and be transferred to a nursing home. This would certainly increase the State's cost and contravene public policy. Indeed, the trusts are a lifesaver for many New Yorkers who wish to remain at home. Medicaid eligibility rules allow a Medicaid recipient a maximum monthly income allowance. Any income in excess of the monthly income allowance needs to be spent on medical expenses before Medicaid will pay. This excess income cannot be spent on non-medical expenses such as shelter. Thus, if an individual's rent exceeds the Medicaid threshold, the Medicaid recipient would be unable to afford his or her rent. Fortunately, Congress and the States have recognized this problem and allow a Medicaid recipient to transfer their excess income into a pooled trust so that it's not counted toward Medicaid eligibility. Therefore, restricting access to these Trusts would conflict with the Governor's stated policy of expanding community care and run counter to the policy inherent in the 1999 US Supreme Court case, Olmstead v. LC and EW, 527 U.S. 581 (1999). This case directed states to integrate the disabled population into the community and avoid unnecessary institutionalization.

Finally, it should be noted that the trust remainders are currently required by Federal and New York law to stay in the trust to avoid Medicaid reimbursement. This amount that remains in the trust benefits other trust beneficiaries with disabilities. The non-profits are not allowed to use those trust remainders for their general operating expenses. Rather, they remain in the trust.

For the foregoing reasons, we respectfully urge that the budget proposal to only allow 10% to remain in pooled Trusts at a beneficiary's death be eliminated.

2. Long Term Care Assessment Centers (Section 23)

The Governor proposes to establish regional Long Term Care Assessment Centers that will replace local social service districts and be responsible for authorizing Medicaid personal care services, the Consumer Directed Personal Assistance Program, assisted living, the proposed Cash and Counseling Demonstration Program, managed long term care programs, and the Long Term Home Health Care (Lombardi and AIDS) programs. The centers will also determine if the individual is eligible for Certified Home Health Agency (CHHA) services beyond 60 days. The pilot will begin for new applicants in January 2010 and in January 2012 will expand to re-assess all ongoing recipients.

While the proposed legislation would be statewide, the change will have a disparate adverse impact in New York City. We are supportive and appreciate the need for a more consistent system, eliminating the vast disparities between counties currently experienced by individuals seeking home and community-based long term care. But the goal of such a radical change must be to ensure that seniors and people with disabilities, including cognitive disabilities such as Alzheimer's disease, can obtain the home care services they need to live in the most integrated setting – in the community, including in New York City. Achieving this goal of providing proper care in the community would also generate true cost savings for the State as New Yorkers would not need to be institutionalized to receive appropriate care.

To successfully develop a system of regional long term care assessment centers, the Legislature must include in the proposal governance by an advisory panel of consumers, providers and advocates with significant input in regard to these features:

- Assessment tools -- The Appropriations Bill would authorize $5 million for development of an assessment tool. We urge that any attempt to create LTC assessment centers be postponed until the new revised assessment process is developed, with the law requiring input from consumers, providers, and advocates in development of the tool, and adherence to legal standards of assessment developed through years of litigation. The tool must also be tested for programs in

different parts of the state before it is implemented. The state should not adopt a care assessment model for the sole purpose of cost control. That would endanger quality of care, infringe on client autonomy, and eventually drive costs up instead of down by forcing people into nursing homes. People needing long-term care do not have the same needs, even with similar diagnoses – social and environmental factors impact the need for care.

- Procedures for center operations and assessments, including incentives built into the contract with the entity selected as the LTC assessment center, to keep people in the most integrated setting, rather than incentives to cut services and costs.

- Establishment of an ongoing panel to review information gathered on utilization, with all data subject to the state Freedom of Information law.

- Due process procedures must be guaranteed within a regionalized Long Term Assessment Center system. When the government delegates the role of gatekeeper and decision maker to a private entity, there is a risk of erosion of due process rights. Consumers must be guaranteed their right to notice and State administrative hearing if a consumer disagrees with a determination.

We also urge that the Department of Health ("DOH") adequately fund and support the LTC assessment centers. Such a failure to develop the needed capacity within the LTC Assessment Centers would lead to bottlenecks and serious delays in assessment for and access to LTC services – as occurred when DOH centralized its system for prior approval of durable medical equipment a few years ago.

Additionally, CHHA services should not be included in the initial phases of the roll out of LTC assessment centers. Unlike the other LTC services which would be assessed by the new regional centers, CHHA services are not currently assessed by NYC and other local districts. Thus the new centers would not only be taking over the heavy workload of the existing local districts for personal care, consumer-directed assistance, and assisted living, but adding to that thousands of cases that would otherwise be approved directly by a CHHA, without local district intervention. This will likely cause severe delays and bottlenecks, and will only further damage the ability of individuals to access needed services.

3. Additional Concerns Regarding Budgetary Changes to Medicaid and Supplemental Security Income (SSI) Benefits.

While we respectively acknowledge the tough choices inherent in budgeting decisions, we must point out three changes that will predominately harm New York's poorest elderly citizens.

First, the Governor proposes to completely eliminate EPIC and Medicaid wrap-around coverage for Medicare Part D beneficiaries. This means that neither EPIC nor Medicaid would pay for any Part D drug if the Part D plan refused to cover it. (Medicaid's wrap-around coverage is limited to 4 specific categories of drugs; EPIC covers all drugs deemed medically necessary by the person's doctor.)

Eliminating wrap-around coverage for EPIC and Medicaid enrollees could directly harm as many as 300,000 disabled and elderly Medicare beneficiaries across New York State if their Part D plans deny coverage of medically necessary drugs. Instead of eliminating the wrap, we respectfully suggest that EPIC should continue the Medicare Part D maximization project enacted by the Legislature last year, which has already shown success in forcing the Part D plans to cover essential medications. Medicaid should continue its limited wrap to provide a safety net for the mentally ill, persons with HIV and organ/transplant recipients.

Second, the Executive budget proposes to include personal care services within the benefit package of Medicaid managed care. Until now, personal care has been "carved out" of these managed

care plans, so that Medicaid enrollees do not need their managed care plan to approve personal care. There is a good reason for the carve-out of personal care. Medicaid managed care plans are paid a monthly capitation rate that is calculated to pay for the average cost of primary and acute medical care. The capitation rate will have to be significantly increased to include the cost of long-term personal care services – otherwise there is a strong incentive for the HMO to deny services as happened last year when DOH expanded the population required to join Medicaid managed care plans to include people on SSI. Many of them suffered as the Medicaid HMOs terminated the CHHA services that they had been receiving for months or even years. DOH was forced to issue a stop-gap policy requiring the HMOs to temporarily continue the CHHA services for 60 days while the HMO reassessed and "reauthorized" the services at its own discretion. Still, this was not enough -- many severely disabled individuals were cut off from CHHA services that had kept them stable in their homes for years. We cannot afford to make this mistake twice.

Third, the Executive Budget proposes to reduce the SSI supplemental State benefit provided to aged, blind and disabled individuals by $24 to $737. Remarkably, this forces the poorest seniors in New York to live on incomes that are less than 82 percent of the Federal Poverty Level, which in 2009 is $902.50/month.

We would welcome the opportunity to meet to discuss our concerns in greater detail.

Respectfully Submitted,

Association of the Bar of the City of New York
Legal Problems of the Aging Committee
Russell N. Adler, Chair

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