



**New York State Department of Health
Budget Hearing – Monday, February 12th, 2018**

**ADRC Position Paper
The Alzheimer's Community Assistance Program**

The Alzheimer's Disease Resource Center (ADRC), formerly known as the Alzheimer's Association Long Island Chapter, has been caring for local families since 1983. ADRC's Executive Director & CEO, Mary Ann Malack-Ragona, has been supporting local families and developing programs and services for ADRC since February 3rd, 2003.

In addition, Ms. Ragona served as the President of the NYS Coalition of Alzheimer's Association Chapters from 2004 until 2012, at which time ADRC separated from the National Association and Ms. Ragona was forced to resign as President of the Coalition. During the time that Ms. Ragona was the Coalition President she worked tirelessly to secure funding for all seven Alzheimer's Association chapters located in New York State.

Now, by virtue of the fact that ADRC is no longer affiliated with the National Association, and the Department of Health changed the process of funding individual agencies, opting for a sole source contract, ADRC and other local agencies lost the AlzCap funding, but we continue to provide extensive programs and services for our local families. ADRC consults with more than 3000 families annually; in addition ADRC provides comprehensive Care & Consultation, we're not just a toll free number – we are a live and compassionate voice, we've educated hundreds of professional caregivers, we work closely with the Suffolk County Sheriff's Office's Project Lifesaver program, for 2018 we are producing our 15th Annual Alzheimer's Disease Education Conference & Expo as well as our 6th Annual Physicians' Outreach Dinner, we publish a comprehensive Resource Guide for our families, we are affiliated with forty Caregiver Support Groups which includes training the Support Group facilitators, we offer our Art Expression Program in twenty-eight sites across Long Island, which also includes staff training, and we offer Art, Music and Equine Therapy programs for individuals with Young Onset and Early Stage Alzheimer's disease. **It is important to note that we offer our programs and services at no charge to our families. It is also important to note that we do all of this work with three full time and two part time staff members.**

ADRC understands the needs of our local community – we are the local community. Our Resource Center was developed for our local community. We are not an agency run by an out of state conglomerate with a CEO whose salary sits in the top ten highest paid non-profits executives in the country. For the past several years I've watched New York State taxpayers' dollars leave our local communities and head out of state. It's time to rethink this process and ensure that our local families are truly the beneficiary of New York state tax dollars.



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**ADRC Position Paper
The Alzheimer's Community Assistance Program (cont'd)**

On August 21st, 2017 we wrote to Howard A. Zucker, M.D., Commissioner of Health for the NYS Department of Health expressing our concerns with regard to the “current sole source approach to contracting for services through the AlzCap funding process.” That letter is attached to this position paper.

On August 30th, 2017 we received a response to the aforementioned letter from David P Hoffman, Director, NYS DOH Bureau of Community Integration and Alzheimer's disease and that letter is also attached to this position paper. While this letter indicated that the NYS DOH would “distribute funds for the Alzheimer's Community Assistance Program through a competitive solicitation process rather than a sole source contract” when the RFA was released we found that this wasn't the case, as only an agency who serviced all of the NYS Counties, upstate and downstate was eligible to apply for the Grant – in other words this would be a sole source contract in disguise.

ADRC is asking that a true competitive bid process be put in place, not just for the AlzCap funding but for all of the grant programs that address Alzheimer's Caregiver Support Programs. If legislation needs to be introduced we request that the criteria for funding be based on quality programs and services and that the bid be open to “true” local entities operating in the State of New York.

We also ask that an investigation be launched to explain how a national organization in Chicago, who is now controlling what were local chapters in New York State and whose CEO's salary clearly violates Executive Order #38, can be given NYS Taxpayers dollars through a grant process. Below is the language from Executive Order #38 as it pertains to the Health Department:

1002.3 Limits on executive compensation (a) Limits on Executive Compensation. Except if a covered provider has obtained a waiver pursuant to section 1002.4 of this Part, a covered provider as defined in this regulation shall not use State funds or State-authorized payments for executive compensation given directly or indirectly to a covered executive in an amount greater than \$199,000 per annum, provided, however, that the department shall review this figure annually to determine whether adjustment is necessary based on appropriate facts and subject to the approval of the Director of the Division of the Budget. Commencing on July 1, 2013, the limits on executive compensation pursuant to this Part shall be effective and applicable to each covered provider on the first day of each covered provider's respective covered reporting period.”

This position paper is written on behalf of the local families we serve who are coping with a diagnosis of Alzheimer's disease or a related dementia. These families need our assistance – these families need your support in seeing that NYS tax dollars stay in New York and that NYS tax dollars are used to care for New York State residents.

Respectfully submitted by Mary Ann Malack-Ragona, ADRC Executive Director/CEO – 2/8/2018



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August 21, 2017

Howard A. Zucker, M.D.
Commissioner of Health
New York State Department of Health
Corning Tower
Empire State Plaza
Albany, NY 12237

Re: The Alzheimer's Community Assistance Program

Dear Commissioner Zucker:

On behalf of the undersigned organizations, each dedicated to providing support and services to persons with Alzheimer's Disease and to their caregivers, this letter respectfully urges the Department of Health to discontinue its current sole source approach to contracting for services through the Alzheimer's Community Assistance Program ("AlzCAP") and, instead, strongly urges the Department to award AlzCAP grants through a competitive Request for Proposal ("RFP") process.

Currently, the Department delegates the distribution of AlzCAP funding through a sole source contract with the Coalition of New York State Alzheimer's Association Chapters, Inc. ("the Coalition"), which then allocates the funds primarily to chapters of the national Alzheimer's Association.¹ As noted below, the current sole source contract, which expires at the end of this fiscal year, is neither mandated by the legislative authorization of the program nor consistent with applicable procurement guidelines. Moreover, the growth of the program in recent years, the emergence of additional, independent Alzheimer's services organizations across the State that are unaffiliated with the national Alzheimer's Association, and a substantial shift in the structure of the national Alzheimer's Association necessitates a reconsideration of the current contractual approach and the adoption of an RFP approach instead.

Legislative history and intent: The AlzCAP program was enacted by the Legislature in 1997 (Chapter 657 of the Laws of 1997, Senate Bill No. 4968-A), but its history dates back at least one year earlier. In 1996, a similar bill (Senate 6725-A) was vetoed by Governor Pataki. (Veto Message #74). As noted in the Governor's veto message, the 1996 bill "stipulate[d] that any funding grants to support this program must be limited to organizations chartered by and affiliated with Alzheimer's Disease and Related Disorders Association, Inc."²

The Governor noted that the Department of Health was already contracting with organizations not affiliated with the national association, including "a school of nursing, an Alzheimer's disease assistance center and several community-based agencies." As a result, the Governor vetoed the bill and invited the bill's sponsors "to consider carefully the wisdom of

¹ At the request of the Department, the Coalition has also entered into a subcontract with CaringKind, which had formerly been doing business under the name of the New York City Chapter of the national association but disaffiliated as of December 1, 2015.

² Veto Message #74, October 2, 1996.

limiting funding to organizations chartered by and affiliated with the Alzheimer's Disease and Related Disorders Association, Inc.”³

To distinguish the 1997 bill from the prior year's vetoed version, your predecessor, Commissioner Barbara DeBuono, specifically pointed out in her memorandum to the Governor's office that this limitation on funding had been removed from the 1997 legislation, making the ultimately approved legislation “a significant improvement” over the 1996 bill.⁴ Even the lobbying firm representing the Alzheimer's Association noted that the 1996 veto related to “limiting funding to organizations chartered by and affiliated with the Alzheimer's Disease and Related Disorders Association, Inc.” and that “[i]n response to this concern, the limitation was deleted from the current statute.”⁵

As a result of this change in the 1997 legislation, the statute provides that “the commissioner is authorized to award grants to applicants approved by the department for the Alzheimer's Community Assistance Program” and that “[a]pplicants shall be limited to not-for-profit corporations which have as their primary purpose providing family intervention services related to Alzheimer's disease, which are designed to postpone or prevent nursing home placements on a statewide basis.”⁶

Accordingly, nothing in the statute compels the Department to funnel support for this program through an entity related to the national Alzheimer's Association and, quite to the contrary, the legislative history of the prior veto and the subsequently revised statute would appear to compel an approach that would make funding available to qualified organizations, regardless of their affiliation (or lack thereof) with the national association. Notwithstanding this unambiguous legislative history, the Department has consistently allocated the funds to the Coalition, which was created and remains governed by entities that are affiliated with the national association.

Procurement Guidelines: The current New York State Procurement Guidelines (“Guidelines”) govern the contracting policies of state agencies and are intended to achieve the goals of the State's procurement process, which is designed to

- Ensure fair and open competition;
- Guard against favoritism, improvidence, extravagance, fraud and corruption;
- Ensure that the results meet agency needs;
- Provide for checks and balances to regulate and oversee agency procurement activities; and
- Protect the interests of the State and its taxpayers.⁷

³ Id.

⁴ Memorandum from Barbara A. DeBuono to Michael Finnegan, Counsel to the Governor, regarding Senate Bill No. 4968-A, September 3, 1997.

⁵ Letter from Hinman, Straub, Pigors & Manning to Governor George E. Pataki, regarding Senate Bill No. 4968-A, September 16, 1997.

⁶ Public Health Law §2006.

⁷ *New York State Procurement Guidelines*, Office of General Services, May, 2014, p. 2 (available at <https://www.ogs.ny.gov/BU/PC/Docs/Guidelines.pdf>).

To advance these objectives, the strong preference embodied in the State Finance Law and the Guidelines is to undertake procurements on a competitive basis. The Guidelines define what limited circumstances might justify entering into a “sole source” contract:

The Sole Source Contract – A sole source procurement is one in which only one vendor can supply the commodities or services required by an agency. The agency must document why the proposed vendor is the only viable source for the commodities and/or services needed by the agency. OSC approval must be obtained for a sole source contract if the contract’s value is over the State Finance Law §112 discretionary threshold [i.e. \$50,000].⁸

There is no basis to justify a sole source contract for these purposes: just as Governor Pataki observed two decades ago, there should be no impediment to the State contracting with a wide array of organizations that provide services to persons with Alzheimer’s disease. The Coalition, the current sole source contractor, was formed by the Alzheimer’s Association chapters in New York State—and, as a result, the current contracting approach seems more consistent with the vetoed 1996 bill than with the enacted legislation. In any case, the Coalition is not the “only viable source” that can supply the services supported by the AlzCAP funding.

Evolution of State support for Alzheimer’s services: From relatively modest beginnings, the State support for Alzheimer’s services has grown substantially over the years, thanks to your support and the support of Governor Cuomo. The current AlzCAP program is now \$5 million annually and is only one of a series of initiatives to support services in this field, including: Regional Caregiver Support Projects (\$15 million annually); Centers of Excellence (\$4 million annually); and Targeted Population Projects (\$1.5 million annually). Whatever may have been the justification for satisfying state contracting requirements when the program remained relatively small, the growing engagement by New York State in supporting critical services in this field requires a more formal and compliant approach.

The changing landscape of Alzheimer’s service delivery in New York State: While the Alzheimer’s Disease services field in New York State was largely (but not exclusively) dominated by the chapters of the national Alzheimer’s Association when the AlzCAP program was initiated, there are today a significant number of organizations that provide services to persons with Alzheimer’s and their caregivers that are not affiliated with the national association and are, therefore, also not aligned with the Coalition that distributes these funds.

In addition to the emergence of some providers of services that have never been affiliated with the national Alzheimer’s Association, two significant entities that were formerly chapters of the national association are no longer affiliated with it. In November of 2012, the Long Island chapter disaffiliated with the national association, becoming the Alzheimer’s Disease Resource Center, because the organization perceived that the national Association was encouraging it to abandon the programs and services that its local families actually needed by way of caregiver support. In December of 2015, the former New York City chapter of the national association also disaffiliated, becoming CaringKind. CaringKind’s departure was precipitated by the

⁸ Id., at p. 8. See also State Finance Law §163(g).

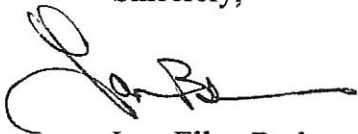
decision by the national Alzheimer's Association in October of 2015 to consolidate all of its chapters into a single corporation—a decision that effectively terminated the independent existence of the New York State chapters and converted the organization into a single, Chicago-based organization. In addition, the Long Island Alzheimer's Foundation, which has operated for 29 years, providing direct adult social day care programs for those afflicted with dementia and their caregivers, has never been affiliated with the Alzheimer's Association, and to date has never received any support of its work from the Coalition

Accordingly, the continued reliance on the Coalition for the distribution of these funds has become increasingly inappropriate. As may be imagined, the disaffiliation of these former chapters, which provide services in regions accounting for the majority of New Yorkers, has created substantial friction and conflict with the national Association. As a result, the Coalition's corporate loyalties are exclusively owed to the national Association and to the remaining affiliated entities that are now, in effect, the "field offices" of the national association. Under these circumstances, expecting the Coalition to discharge its contracting responsibilities and to allocate these expenditures in an even-handed manner is simply unrealistic. If the New York State procurement process, as noted above, is intended to "ensure fair and open competition" and "guard against favoritism, improvidence, extravagance, fraud and corruption," it is incumbent upon the Department to discontinue the current contracting approach and fulfill the intent of the 1997 legislation.

For all of these reasons, the undersigned organizations respectfully request that the Department issue a competitive RFP for these services and enter into contracts with the successful bidders when the current sole source contract expires on March 31, 2018. We urge the adoption of a competitive procurement process without any expectation that any of the undersigned is necessarily assured to be successful in that process or to receive any additional funding as a result. We believe, rather, that the establishment of a fair and competitive contracting process will, in the end, improve the delivery of services to persons with Alzheimer's Disease and their families and caregivers and will avoid any perception that the allocation of these funds may be distorted by real or perceived conflicts of interest.

Your consideration of this request is very much appreciated.

Sincerely,



Lou-Ellen Barkan
President & CEO
CaringKind



Mary Ann Malack-Ragona, MBA
Executive Director & CEO
Alzheimer's Disease Resource Center



Tori Cohen, LCSW
Executive Director
Long Island Alzheimer's
Foundation

cc: Mark Kissinger
David Hoffman



Department of Health

ANDREW M. CUOMO
Governor

HOWARD A. ZUCKER, M.D., J.D.
Commissioner

SALLY DRESLIN, M.S., R.N.
Executive Deputy Commissioner

August 30, 2017

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Dear Ms. Barkan, Ms. Malack-Ragona, and Ms. Cohen:

I am writing in response to your letter to New York State Commissioner of Health, Howard A. Zucker, M.D., J.D., regarding your request that the New York State Department of Health (Department) distribute funds for the Alzheimer's Community Assistance Program through a competitive solicitation process rather than a sole source contract.

The Department has conducted a Request for Information related to this funding. More than one response was received; therefore, the Department has determined to issue a Request for Applications for these funds.

I appreciate your interest in this funding and in the provision of support services to caregivers of individuals with Alzheimer's disease and other dementias.

If you have further questions, please contact the Alzheimer's Disease Program at 518-486-6562, or via email at alz@health.ny.gov. Thank you.

Sincerely,

David P. Hoffman, D.P.S., C.C.E.
Director, Bureau of Community Integration and
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Division of Long Term Care
Office of Health Insurance Programs