

March 28, 2012

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HHS Office for the Assistant Secretary
for Planning and Evaluation
Department of Health and Human Services
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

RE: Professor, Researcher and Author comments on the Draft Framework for the National Plan to Address Alzheimer's Disease

Thank you for inviting the public to comment on the U.S. Department of Health and Human Services "Draft Framework for the National Plan to Address Alzheimer's Disease." For over three decades I have worked as an educator at the University level, and therapist with individuals who have either been just diagnosed with early on-set of Alzheimer's Disease, mild- to moderate stages of the disease as well as late stage Alzheimer's disease. In addition, I have taught at Colleges and Universities across the United States as well as in many countries internationally. Being a two time Fulbright Scholar in Global Health Studies, I have dedicated my academic career to both teaching, researching and authoring creative and innovative approaches on how to best provide programming to those afflicted with this disease. I welcome the opportunity to provide recommendations for your consideration.

In recent years, various non-pharmacological approaches to care such as creative arts-based programming; cognitive stimulation; exercise and movement programming; meditation; learning methods; sensory therapy, and cognitive training are recognized in small scale studies and are the basis of research information taught and practiced at the University level in career areas such as Therapeutic Recreation, Creative Arts Therapies, Movement and Dance Therapy and Art Therapy. These non-pharmacological approaches have emerged as a grassroots movement responding to an evolution of evidence, put into research and implemented in Social Adult Day Programs, Assisted living Facilities, and Long Term Nursing Facilities.

However small these studies, research is continuing to suggest that some individuals will slow the progression of dementia and have the potential to improve or revert back to normal memory with early interventions due to structured cognitive stimulation (Pressley, J., Trott, C. & Tang, M., 2003; Chertkow, H., et al., 2001). Additionally, there is evidence to suggest that activities in the mental, physical and social domains have protective effects against cognitive decline and dementia (Flatiglioni, et al. 2004; Gilley, W., Wilson, L., Bienias, L., Bennett, A. & Evans, A., 2004; Claire, L., Wilson, B., Carter, G., Roth, I. & Hodges, J., 2004; Davie, J., et al., 2004). More specifically, continued active participation in life through social involvements and activities that are individualized and person centered to each individuals needs and skills have been documented to enhance feelings of self esteem, self worth and directly impact overall quality of life (Pruessner, J., Lord, C., Meaney, M. & Lupien, S., 2004; Manly, J., et al., 2005; Kumara, R., et al., 2005). A National study of all research related to early stage dementia indicated that the need for psychosocial support for persons newly diagnosed should take place soon after receiving the diagnosis to prevent dropping social support networks, cognitive decline and leading to increased institutionalization rates (Brodaty, H., Gresham, M., & Luscombe, G., 1997; Fernandez-Ballesteros et al., 2003). In a review of the literature regarding early stage AD it has been documented that multi-modal approaches have the most significant outcomes (Burgener, S., et al., 2007). The TTAP Method, a multi-modal approach has been

documented in a pilot study (Alders, A. & Levine Madori, L., 2010) to improve cognition in Hispanic elderly in a Social Adult Community Day Center in Buffalo, New York and in a research study with Rehabilitation Patients at Helen Hayes Hospital the method proved to increase overall feelings of self control and pain management (Levine-Madori, L., 2009).

Research in the area of non-pharmacological approaches to Alzheimer's care is still being ignored, and yet it continues to remain the most economically sound approach. In a data collection in 2010 on a Gero- psychiatric unit at Lyndon Oaks at Edward Hospital located in Naperville, Illinois, staff was trained in The TTAP Method. Pre- training data collection documented the unit had an average of 90 hours of aggressive interventions a month. These interventions were carried out by a Nursing Supervisor. Six months into staff implementing of thematic person-centered creative arts programming the aggressive behaviors went down to an average of 4.6 Nursing Interventions. Falls went from an average of 5 per month to 3, this statistics validate a direct healthcare savings of over \$80,000.00 in just a six moth period.

<http://www.levinemadori.com/content/site/educational-courses.php> .

A world without Alzheimer's, might very well be a real possibility in the future. However, the current 5.4 million people who currently have the disease and the estimated 10,000 people daily diagnosed each and every day will still need daily non-pharmaceutical innovative programming, treatment and care. As an Art Therapist, Recreation Therapist and Ph.D. it is my belief that the current research agenda is narrow in scope and leaves research in the non-pharmaceutical -creative arts completely out of the discussion. For decades we as a society have poured millions of dollars into pharmaceutical research, which to date has yet to make an impact. It is my belief that it is crucial at this point in time, just as the baby boomers are starting dramatically impact the "graying of America". As you probably are aware, it is estimated by the National Association on Alzheimer 's disease, in 2011, that one of every 8 baby-boomers are predicted to have some form of cognitive impairment in their lifetime.

The time for researching the non-pharmaceutical approaches and putting research into practice is now! Those who have dedicated their lives to people afflicted by this disease process understand that these individuals LIVE with the disease for many years. The average person diagnosed with Alzheimer's Disease now lives 15 years and must be given meaningful and person-centered daily therapeutic interventions. Without research we cannot move forward in the healthcare areas such as Art Therapy, Recreation Therapy, Music Therapy, etc. to provide research based, best practice approaches. Please know that these healthcare fields in the Creative Art Therapies, Therapeutic Recreation, and Music Therapy are in fact where daily treatment and ongoing cognitive, social, emotional and physical stimulation comes from. Research money is needed to be earmarked for these healthcare professionals and the research that they do in non- pharmacological approaches to Alzheimer's care.

Thank you for the opportunity to share thoughts and suggestions with you.

Sincerely,

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