

Medical Center

In the tradition of the Medical College of Virginia

30 March 12

Virginia Center on Aging

Advisory Council on Alzheimer's Research, Care, and Services
c/o Helen Lamont, Ph.D.
HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201

Theater Row
730 East Broad Street
P.O. Box 980229
Richmond, Virginia 23298-0229

804 828-1525
Fax: 804 828-7905
TDD: 1-800-828-1120
www.vcu.edu/vcoa/

Dear Dr. Lamont:

The Area Planning and Services Committee (APSC) on Aging with Lifelong Disabilities, which I serve as chairman, respectfully wishes to make comments on the Draft National Plan to Address Alzheimer's Disease. The APSC is a regional coalition comprised of some two dozen organizational and individual members from Chesterfield, Hanover, and Henrico counties and the city of Richmond, Virginia, representing intellectual disabilities, parks and recreation, residential services, blindness and visual impairment, communities of faith, higher education, family caregivers, and more.

The APSC works to address both the opportunities and challenges that present themselves as more adults with lifelong disabilities grow into later life. In effect, the APSC acts as a creative form of *de facto* public policy, trying to respond in the present to issues that formal regulations have not yet incorporated. For instance, how can aging-related services that are offered only to adults ages 60 and above respond to persons with lifelong disabilities who may manifest "aging" behaviors prematurely? In response, the APSC offers training workshops and statewide conferences, has developed health screening tools and DVDs on healthy diets and nutrition for adults with lifelong disabilities, and more.

Increasingly, service providers and family caregivers are pressing us for more focus on matters related to dementia with intellectual disabilities and other developmental disabilities. Our fall 2011 workshop did and our June 2012 statewide conference will concentrate on dementia care with lifelong disabilities. Adults with Down syndrome and other intellectual disabilities present new challenges to providers and families. Premature expression of Alzheimer's Disease by adults with Down syndrome generally precludes their engagement in aging-related services funded by the Older American Act which stipulates age 60 for eligibility. Dementia disrupts group homes for individuals with lifelong disabilities, for it overwhelms staff's ability to respond in the face of other continuing needs by those without dementia and breaks the bond of community that the adults with disabilities have developed.

At the same time, the overwhelming majority of today's older adults with lifelong disabilities have grown old in family contexts, in the care of their parents, not in an institutional setting. These caregiving parents, now quite advanced in age, are often under-recognized and under-reinforced by outside services, and the presentation of dementia is often more than they can handle. There are today about one million adults with lifelong developmental disabilities who have reached age 60 and beyond. Again, the great majority have done so through the continuing care of the parents and families. These parents and families need and deserve help.

The Draft National Plan does make mention of intellectual disabilities but we respectfully request that the Draft National Plan make a fuller focus, to include at least the following:

- 1) Attention to the special circumstances attendant upon the relatively premature expression of dementia among adults with Down syndrome, an expression that occurs before the individual's own eligibility for aging-related services funded by the Older Americans Act.
- 2) Attention to the expression of dementia among adults with other developmental disabilities (e.g., cerebral palsy, non-Down intellectual disabilities) and the consequences of the co-morbidity of dementia and the lifelong disability.
- 2) Attention to the growing need of managers, service providers, and policy makers with the developmental disabilities service sector for high quality training on Alzheimer's Disease and other dementias, training that includes both conceptual and practical day-to-day management content.
- 3) Attention to the public reliance upon family caregivers as the mainstay of the long-term care system, as it relates to aging with lifelong disabilities, and to the critical needs of these family caregivers for training in and support about caring for someone with intellectual and/or developmental disabilities who develops Alzheimer's Disease or another dementia.

We thank you for considering our recommendations. With best wishes, I remain

Yours sincerely,

A handwritten signature in dark ink that reads "Edward F. Ansello". The signature is written in a cursive, flowing style.

Edward F. Ansello, Ph.D.
Director