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## Meeting the Challenges and Opportunities of Aging with Lifelong Disabilities: The Area Planning and Services Committee

Allison Wilder, M.S., CTRS, and Edward F. Ansello, Ph.D.

*Allison Wilder, MS, CTRS*, is a faculty member in the Department of Recreation, Parks and Sport Management at Virginia Commonwealth University (VCU). She completed an externship with the APSC during summer 2004. *Edward F. Ansello, Ph.D.*, is the Director of the Virginia Center on Aging and Professor in the Department of Gerontology at VCU.

### Educational Objectives

1. To generate awareness of needs and capacities of aging adults with lifelong disabilities and their effect upon human services
2. To understand the challenges and opportunities facing aging adults with lifelong disabilities in accessing appropriate community supports and services.
3. To illustrate the benefits of intersystem collaboration among human services providers through the vehicle of an Area Planning and Services Committee.

### Background

We are well aware of the "graying of America." We are also aware of the remarkable heterogeneity of the older adult population and the challenges inherent in attempting to set policy, develop programs, and administer services for such diversity. If we take a closer look at the demographics of our aging citizenry, we will see an unprecedented subgroup emerging, elders living with lifelong disabilities.

Most of us take for granted an established rhythm to the life course: we work most of our adult lives, retire, and then enjoy our golden years. But for individuals with lifelong developmental disabilities such as mental retardation, cerebral palsy, and autism, preparing for old age is a relatively new phenomenon. For example, in just the past 20 years the median life expectancy for a person with Down syndrome has nearly doubled, increasing from 25 years in 1983 to 49 years in 1997 (Yang et al., 2002). Further, it is estimated that the overall population of older adults with lifelong disabilities will double within the next 30 years (Heller, Janicki, Hammel, & Factor, 2002). Some 60% or more of today's older adults with developmental disabilities live at home with family members. Another sizeable percentage lives in group homes or other settings in the community. Only a small minority lives in any type of institutional facility. While those at mid-life or younger present a different picture, having benefited from "mainstreaming" legislation as children, older adults in their forties and beyond tended to grow up and older relatively invisibly within the community. Today, about 25% of these older adults live with a caregiver who is over the age of 60. It is a startling reality that aging parents who are in their 60s, 70s, and 80s are still providing daily care for their adult children who are in their 40s, 50s and 60s. In addressing aging with lifelong disabilities, therefore, human services providers must plan for "two-generation geriatric families." (Janicki & Ansello, 2000)

The increasing longevity of people with lifelong disabilities creates interesting dilemmas. As a society, we can take great satisfaction in the social and medical advances that have led to longer and more vital lives for individuals with disabilities. Yet these advances have created a subgroup that tends to fall through the cracks in terms of policy development, health care and human services delivery. For example, older adults with lifelong disabilities challenge developmental services systems that are oriented to early intervention. Moreover, we should be gravely concerned about one of the primary mechanisms that fostered their growing older, namely, their parental caregivers. How do we meet the individual's continuing, and likely increasing, need for services and supports as their primary caregivers "age out" of their ability to provide daily care. Who will provide the supports and services to help individuals who wish to

stay in their homes? How can we reinforce existing family caregiving? Where should services be provided? Will funding will be available for training and services? Who will advocate on behalf of those who need help?

### Case Study: The APSC as Innovation

As noted, individuals who grow older with lifelong, developmental disabilities are in danger of falling through the cracks of our fragmented human services systems. Up to now, there has been little history of effective communication or collaboration between and among the various service systems that comprise the disabilities and aging networks, forcing providers into a reactive rather than a proactive mindset. At least one national study of all of the state level aging and state level developmental disabilities units has found that aging with lifelong disabilities is neither a funding nor a service priority for either system (Coogle, Ansello, Wood, & Cotter, 1997) Changing this mindset is essential if we are to meet the needs and strengthen the capacities of aging citizens with lifelong disabilities and their families. Responding to these realities, a group of service providers, planners, health care professionals, and others created the Area Planning and Services Committee for Aging with Developmental Disabilities (APSC) in the greater Richmond area in summer 2003 as a multi-agency collaboration to plan and provide age-sensitive programs and supports for the citizens in our communities.

Forming an APSC is a critical component of a strategy called the Integrated Model of Service for Older Persons with Developmental Disabilities (see Janicki & Ansello, 2000). The Model was developed and field-tested over time during the federally supported Partners I, II, & III research and demonstration projects in Virginia and Maryland, a sustained effort to improve intersystem cooperation and the capacities of service providers, older adults with lifelong disabilities, and their family caregivers. The Model maintains that meaningful response to the needs and capacities of aging adults with lifelong disabilities requires intersystem cooperation, and that this, in turn, is made likely through the three key strategies of collaboration, outreach, and capacity building. Collaboration should occur at state and local levels. The APSC is the local effort.

The APSC from the Greater Richmond Metropolitan Area is a vibrant mixture of members who are leaders in the fields of disability, aging, health services, parks and recreation services, communities of faith, higher education, and more, plus family caregivers and others. They share a commitment to the well being of aging adults with lifelong disabilities and their family caregivers. Collaborating agencies designate in writing those who represent them in the APSC. Members represent the disabilities, health care, aging, parks and recreation, faith community, and other human service agencies in the City of Richmond, Chesterfield, Hanover, and Henrico counties. They meet monthly, becoming better acquainted with each other's organizational philosophies, priorities, and funding streams. Each meeting contains an overview of a member agency, discussions of needs and opportunities, and creative initiatives for staff training needs, the education of the general public, and more.

The focus of the APSC is to promote thoughtful understanding of issues, collaboration among systems and providers, outreach to older adults with lifelong disabilities and family caregivers, and help in building the capacities of formal and informal care providers through education, training and information. The following composite case represents real initiatives undertaken by the APSC.

*Betty is 54 years old and has cerebral palsy. She has lived at home all of her life. She and her 72-year old mother share a modest home on the outskirts of Richmond. Betty has been working faithfully at the same sheltered workshop program for the past 15 years assembling medical products. She has been a reliable employee with a strong work ethic and a desire to do a good job. Lately, Betty has begun to miss work due to "not feeling well." Her employer has noted that her productivity has declined and that she is having difficulty completing a full day of work. Betty would like to cut back from full time work, but cannot stay alone at home as her mother still works in order to make ends meet. Betty and her mother will need to find alternative plans if Betty cannot, or does not want to, continue her demanding work schedule.*

### APSC Response

Betty represents the dilemma of success. She has grown older in a support system that is relatively unprepared for aging-related issues. She wants to retire and needs a retirement plan. There are services that would be appropriate but, as an aging person with a lifelong disability, Betty faces a predicament imposed by the historical structure of our service systems. While aging network programs may be better suited to meet her needs, at age 54 she does not meet the legal age of eligibility for Older Americans Act-funded programs, i.e., 60 years of age. APSC members discussed her situation and worked to resolve the dilemma inherent in serving a new population whose needs span two or more service networks. The APSC identified disparate eligibility criteria in various health, transportation, and social programs operated by the aging network and disabilities systems. Out of this dialogue came, among other things, the implementation of a new approach to using a valuable existing resource, the Friendship Café, as a first step for Betty.

The Friendship Café is a nutrition program sponsored by Senior Connections, the Capital Area Agency on Aging.

Funded by the federal Older Americans Act and administered through the Virginia Department on Aging, the Friendship Café is open to anyone age 60 or older who meets eligibility guidelines. In addition to providing a nutritious noon meal, the program offers social and health promotion activities. The program would be perfect for Betty if she were older. As Betty is only 54 years old, she does not meet eligibility guidelines. Rather than denying Betty access on age alone, APSC members responded with thoughtful resource sharing to secure meal funding for Betty through other channels that allow her to take advantage of the social and health promotion aspects of the Café and still partake in the meal program.

*Betty's mother has begun to experience health problems that make it very difficult for her to help Betty with her care needs. She has a debilitating arthritis and cardiovascular problems. She wants to continue the lifelong pattern of living with her daughter, but it is likely that Betty's mom will soon be unable to care for her, which may mean that Betty would need to move into a group home or other facility to receive the assistance she needs. Moving is likely to be very traumatic for Betty as she will face losses on multiple levels when she leaves her mother's house, the only home she has ever known.*

### APSC Response

Given mother's and daughter's preferences to maintain their shared home, the APSC's first step was to initiate actions that would strengthen or maintain the mother's health. Visiting nurses assessed her overall health status, while a short-term home chore service helped with the more pressing current needs. The APSC identified the need for Betty's mother to explore and to initiate plans for the continuing care of her daughter after her own incapacity to do so; this so-called "permanency planning" is complex, involving legal, financial, and familial actions. The APSC also acknowledged the eventual reality that Betty will need help understanding why she must move and coping with the loss associated with leaving her mother's home. The APSC has undertaken an initiative in loss and bereavement issues for aging persons with lifelong disabilities, with plans to offer training and outreach. Local experts were brought in to consult with the APSC's Loss and Bereavement Subcommittee. It examined research on loss and grief, finding little related to adults with lifelong disabilities. Consulting counselors advised training for direct service staffs on loss and grief associated with the many transitions these adults experience with advancing age: loss of home, parents, friends, program staff who change jobs, etc. The APSC is formulating training programs for area service providers to enhance their ability to understand loss and bereavement behaviors, to assist elders with coping with such loss, and to screen for the need for expert help in dealing with problems associated with loss and bereavement. The intention is to have trained service providers in place by the time Betty moves from home.

### Conclusion

As shown by their responses to the needs and concerns of aging adults with lifelong disabilities, the greater Richmond APSC has become a proactive vehicle to address problems and opportunities. Each APSC member carries the commitment of his or her respective agency, having been designated to participate in the collaborative processes of identifying community needs, sharing resources, resolving problems, and creating innovations that serve our elders with lifelong disabilities and their family caregivers. By working together, APSC members have created a virtual organization, one without a building or specific funding stream but one that is greater than its separate parts. As APSC member Debbie Burcham of Henrico County Mental Health/Mental Retardation remarks, "By partnering disability services with aging services, both types of providers benefit. Providers who are very skilled in supporting persons with disabilities can share their skills with those who provide services to the aging and vice versa."

### Study Questions

1. Identify the challenges and service gaps aging consumers face in accessing community supports and services.
2. What are the three key strategies of intersystem cooperation and how has the Richmond Area APSC carried out this charge?
3. Describe how the APSC can assist human services providers, consumers, and family caregivers to maximize service utilization.
4. Identify how intersystem collaboration in the form of an APSC can directly benefit someone like Betty and her mom.

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## **From the Executive Director, Virginia Geriatric Education Center**

Iris A. Parham, Ph.D.

The VGEC has some exciting projects going. We are celebrating our good fortune in receiving a competitive supplemental grant from HRSA, our main funding source. The focus of this project will be Ethical Decision-Making. We are in the midst of our fall training for our new Virginia Department of Social Services contract; the topics for this fall are: Managing Aggressive Behavior (this training was completed September 29th with 240+ participants); Overview of Mental Disorders; Caring for Others, Helping Yourself: Mental Illness and Dementia; and Individualized Service Plan. We are continuing work on our \$1 million Department of Medical Assistance Services training and evaluation project for direct service community workforce; there will be much more information on this training in the next issue.

We are also sending out invitations for partnership to other GECs to work with us on future videoconferences. Currently, four GECs: Virginia, Pennsylvania, Western Reserve and Mountain State are partnering with the Veterans Health Administration's Employee Education System to present a series of annual videoconferences in areas of critical need. Through this partnership, we have produced conferences on End of Life, and Parkinson's Disease. Our next joint presentation will be in Spring 2005 on the topic: "Alcohol and Drug Abuse in Older Adults: Diagnostic and Treatment Challenges." Our preliminary draft of the program includes an introduction with discussion of the epidemiology of drinking and substance abuse among elders; description of the barriers to diagnosis and treatment; description of the age-related changes that affect the response to these substances; a discussion of the dangers of drug-alcohol interaction and a discussion of the consequences of untreated abuse. This conference will focus on prevention; assessment and diagnosis; and intervention and treatment. We are actively seeking sites who would wish to take part in this conference. If you are interested in partnership or participation, please contact the VGEC at (804) 828-9060.

Additionally, if you are interested in hearing more about our statewide geriatrics module training please contact the VGEC.

Lastly, we would like to formally thank Dr. Janet Watts for her long and commendable service to the VGEC; she just retired from VCU and we wish her well. We welcome Ms. Maggie Butler, a recent VCU graduate, who has joined the VGEC full time and we are delighted to have her on our team.

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## **From the Director, Virginia Center on Aging**

Edward F. Ansello, Ph.D.

### *What We Didn't Hear*

The presidential election campaign of 2004 has been significant in my mind for what has NOT been deeply discussed: the unprecedented aging of this nation and its multiple consequences. Unless I missed it, neither candidate seemed to incorporate viscerally or to plan strategically for the greatest shift in population dynamics that this nation has ever seen. Nor did the vice presidential candidates communicate awareness of this reality.

Statistics about life expectancy from birth or likely number of years remaining from age 65 translate in the real world, the world a president must manage or at least accommodate, into facts that are previously unwitnessed. More older Americans than ever before, more two-generation geriatric families, more older adults with lifelong disabilities or acquired late onset disabilities, more potential retirees (those ages 55-64) but fewer entering workers (those ages 15-24), and, of course, the 800 pound gorilla (or should we say guerilla?), more demand on the Social Security system. Even Alan Greenspan voiced concern for its well being this fall in comments that drew sharp but short-lived attention.

Neither of the principal candidates exploited this opportunity to propose thoughtful adjustments to the aging of the Baby Boom and the overall aging of the nation. Can the current eligibility ages for Social Security be maintained? Will privatization work for different socioeconomic groups? Can or should the federal government maintain hands off when so many defined contributions pension plans go bust? (ERISA covers, essentially, only defined benefits plans.) What lessons do such busts augur for larger scale privatization? Is the only help for the victims some last resort Medicaid or SSI assistance?

At the same time, about half of the experienced , career senior executives directing the federal government will be eligible to retire with the next five years.

Another reality ignored is that long-term care in America is basically caring by families. Daughters, spouses, sons, in-laws and relatives keep loved ones out of expensive facilities for as long as they can. Long-term care is, in some ways, a house of cards built on a base of familial caring. What happens when the caregivers age out of this capacity and who cares for the carers? Is there any plan to strengthen family caregiving? Does the Baby Bust that followed the Baby Boom mean more care-related costs would be have to be assumed by government? As simple as these questions are, for they have been stated and discussed more elegantly in the professional literature, I heard and read little from the candidates that related to them.

Nor did I hear either candi-date articulate an appreciation of the interrelatedness of global aging, the Baby Bust, a potential reliance upon young immigrants for labor and the effect of this reliance upon legal and illegal immigration, health care for an aging nation in the face of too few geriatricians and a looming shortage of primary care physicians, and the tension between pay for service medicine and national health care. The world is a much smaller place today than ever before. What happens in one country demographically can affect its productivity and economics, affecting the price and attractiveness of its goods, affecting the health of its labor force, affecting its relationships with other nations, and on and on.

I would not presume to offer grand solutions. The issues are too complex. What I do observe is that the present cohort of leaders is not raising the questions, let alone proposing some answers. Future presidents will have to confront the 800-pound gorilla/guerilla and the sundry associated matters noted above. The clock is ticking. Do these leaders hear it?

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## **From the Commissioner, Virginia Department for the Aging**

Jay W. DeBoer, J.D.

### *Virginia's First "Stay Safe and Mobile Expo"*

Virginia's first "GrandDriver Stay Safe and Mobile Expo" for senior drivers and their families took place on Thursday, September 23 at The ACCA Temple in Richmond. The public was invited to attend this event and there was no charge for admission. The event was part of The Virginia Department for the Aging's GrandDriver public awareness initiative, which brings attention to the state's many sources of information and technology available to help older drivers "stay safe and mobile."

Maintaining independence through mobility for as long as possible is critical to the health and well-being of older Virginians. The "Stay Safe and Mobile Expo" was created because many seniors and their families are simply not aware of the information or technology available to help them maintain their independence. The Expo setting allowed the Department to bring seniors together with aging specialists and service providers, such as driving assessment facilities and sources of specialized adaptive equipment, in a friendly, convenient setting. Participants in the "GrandDriver Stay Safe and Mobile Expo" included members of the Mid-Atlantic American Automobile Association, AARP, the Virginia Department of Rehabilitative Services, occupational and physical therapists from CJW Medical Center as well as the Woodrow Wilson Rehabilitation Center, the Virginia Assistive Technology System, and many others.

Representatives from the Virginia Department of Motor Vehicles (DMV) were available to explain and answer questions about new and existing laws that affect older drivers including the new vision test required for license renewals by those drivers eighty years old and older.

The "Stay Safe and Mobile Expo" was an activity of the GrandDriver awareness campaign. While a great number of older drivers may be good drivers, the physical changes associated with aging can ultimately affect a person's ability to drive safely. To insure that the public is aware of this, Virginia's GrandDriver campaign has been developed to provide

information about aging and driving. GrandDriver encourages the public - particularly drivers over 65 and their adult children - to learn more about the effects of aging on driving ability, and encourages dialogue on this issue. The GrandDriver web site provides information on the signs to look for in determining whether or not age has affected a person's driving abilities. It also offers information on methods that can be used to help an older driver continue to drive safely and lists resources for those who may need assistance. For more information, call the Virginia Department for the Aging toll free 1-800-552-3402 or visit the GrandDriver web site at [www.GrandDriver.net](http://www.GrandDriver.net).

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## Focus on the Virginia Geriatric Education Center

### Maggie Butler, B.S.

Maggie Butler joined the VGEC as a work-study student in February 2004 where she assisted with implementation of the Department of Medical Assistance (DMAS) Enhanced Care Assistant Training program. She quickly became a valuable member of the VGEC team and in August of this year she took a full-time position as Program Support Technician for the DMAS grant, as well as the Virginia Department of Social Services (VDSS) contract.

Ms. Butler received her Bachelor of Science in Psychology with a minor in Religious Studies from Virginia Commonwealth University in May. Currently, she is enrolled in the Rehabilitation Counseling M.S. program. She plans to pursue a Doctoral degree in Health Related Sciences and hopes to work with children with sensory and learning disabilities.

When Ms. Butler is not working or studying, she enjoys playing the flute as well volunteering at the Westend Boys and Girls Club.

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## Focus on the Virginia Center on Aging

### Nancy Podbesek

Nancy Podbesek is a native Virginian who began working for the Virginia Center on Aging this summer. She knew Dr. Constance Coogle, having met her off-campus in Carytown. Nancy was completing a research paper for her experimental methods class in pursuit of her undergraduate degree in psychology at VCU. Over time, Nancy and Connie shared information about their respective investigations. Nancy says, "As we discussed our mutual interest in psychological research, Dr. Coogle made her research work sound intriguing, and gerontology is a related field that I hadn't explored much. It made me realize that I could really make some contributions in that area." One day Dr. Coogle expressed her worries about the impending loss of her long-time research assistant, Katie Young. "She knows what I need before I know I need it. I don't know what I will do without her," she complained. Nancy said that she would like to step in, and the rest is history.

While completing classes to be certified as a massage therapist in Williamsburg, Nancy was drawn to the academic environment of VCU and enrolled in the pre-nursing program here. In her second semester she was accepted into the nursing program itself. During this time she was working as a personal care assistant providing home care for a Korean man who relied upon a wheelchair. Though pursuing a degree in nursing, she was minoring in psychology. She decided that the latter area was her passion and made the choice to major in it, citing its type of one-on-one interaction with people.

Nancy is graduating this summer with a Bachelor of Science in Psychology from Virginia Commonwealth University. She is looking forward to gaining research experience that will prepare her for a post-baccalaureate degree. She will be assisting Dr. Coogle in one of her several evaluation studies, the analysis of data from nursing assistants collected by the Alzheimer's Association through their train-the-trainer program. Nancy will also be helping Drs. Coogle and Osgood evaluate their multi-year training project on healthy and unhealthy behaviors in older adults in Delaware, and processing data from the VGEC's Enhanced Care Assistants Training.

Nancy loves summer, for she spends her free time going to the beach, swimming, and fishing in the Tidewater area. She is an amateur photographer and likes working on cars with her family. She is learning the ancient practice of Mehndi (henna body art) and is looking for volunteers to display her skills in temporary body designs.

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## VCU/Reynolds Grant Update

The VCU/Reynolds Partnership in Geriatrics Education is now in its fourth year. Strong emphasis is being placed on geriatrics education for community physicians. The grant staff has planned a Thursday evening dinner series beginning in September 2004 and wrapping up in May 2005. VCU faculty and guest speakers will be teaching a variety of topics in geriatrics. A half-day workshop titled "Pressure Ulcers and Wounds Care Management for Primary Care Physicians" is planned for November 13, 2004. Many of our Geriatrics Scholars have already registered for these events. We have been successful with the active participation and overall retention within our Scholars Program. Several have surpassed the 30-credit CME goal established in year 1 of the grant. In May, 2005, all Scholars reaching that goal will be invited to a celebratory dinner at the VCU Ballroom, held in conjunction with the 10th Anniversary celebration of the Foundations of Clinical Medicine department.

The grant continues to carry out the mission of educating medical students and residents. M-II Geriatrics House Calls are in full swing, and an average of five internal medicine residents and one OB/GYN per month participate in a geriatrics rotation, going on house calls, to nursing homes, clinic, and/or geriatrics consults. Non-medicine residents continue to receive didactic lectures and cases studies from the geriatrics faculty, as well, such as Dr. Christine Tully's September 16, 2005 lecture to general surgery residents on pre-operative assessment.

Dr. Arline Bohannon has initiated a weekly geriatrics journal club and case conference, effective at the beginning of academic year 2004-2005. All geriatrics residents, faculty, fellows, nurse practitioners, pharmacists, and medical students are encouraged to attend. It is held Thursdays from 1:15 - 2:00 p.m. in the geriatrics conference room on the ground floor of the North Hospital (G-182). Topics include long-term care, ambulatory care, and in-patient issues. The experience

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## VGEC Announces Program for Fellows and Scholars in Ethical Decision-Making

The Virginia Geriatric Education Center is pleased to announce a new training program for health professionals: the Ethical Decision-Making Fellows and Scholars Program. This training will be developed and delivered under a grant awarded to the VGEC in July by the Health Resources and Services Administration (HRSA). The project, called "Right Choices: Ethical Decision-Making in the Health Professions," is designed to expand the training of health professionals in the ethical issues of decision-making as they relate to an increasingly diverse geriatric clinical practice. Training will be focused primarily on ethical issues of patient autonomy in care planning and end-of-life care. Support is available for 60 Fellows and Scholars from health professionals in medicine, nursing, pharmacy, psychology, social work, and the allied health professions, including health administration.

The project will work collaboratively within Virginia Commonwealth University and with community partners. With the guidance of an Interdisciplinary Development Group and a Health Practitioners Group, the VGEC will develop training modules and materials appropriate to each discipline and setting. Existing training mechanisms such as Grand Rounds and Interdisciplinary Forums will be used to present training.

In addition, CD and web-based modules will be produced. These modules will be developed with the assistance of ethical decision-making experts within each discipline. Right Choices will also be integrated into the VGEC's Lifelong Health Care Initiative (LLHC) that provides a multi-tiered program designed to maximize lifelong involvement in health careers for both students and practitioners from more than 20 disciplines.

The VGEC's Executive Director, Dr. Iris Parham, is the Principal Investigator of the project. The Associate Directors of the VGEC, Dr. E. Ayn Welleford and Dr. J. James Cotter, also have principal roles in this project. Dr. Welleford will manage the development of content and Dr. Cotter will provide operational management. For more information contact Lucy Lewis at the VGEC by phone at 804-828-9060 or by email at [blewis@vcu.edu](mailto:blewis@vcu.edu).

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## Philip Morris Employee Community Grant Fund Awarded to VGEC

The VGEC was recently awarded a grant of \$35,000 from the Philip Morris Employee Community Grant Fund, locally managed in Richmond. This grant will be used as seed funding for expansion of the VGEC's Lifelong Health Care Initiatives (LLHC), which addresses aging awareness and educational outreach activities focused on area community and business organizations. Another small grant from Walmart Corporation, Colonial Heights location, will enable outreach to the fast-growing Hispanic population in this area, with the goal of increasing awareness of possibilities and participation in health careers. This grant will be used to overdub into Spanish a new video/dvd set of seventeen different health professionals's interviews, which is aimed at soliciting interest in medical careers from a community's student population.

## COMMONWEALTH OF VIRGINIA

## Alzheimer's and Related Diseases Research Award Fund

## 2003-2004 ALZHEIMER'S RESEARCH AWARD FUND FINAL REPORTS

**UVA James P. Bennett, M.D., Ph.D. and Bradley Miller, M.D., Ph.D. (Department of Neurology/Division of Neuropathology) "Mitochondrial DNA Deletions and Mutations in Alzheimer's Disease Brain Neurons"**

This research examined the genetic contribution mitochondria make to Alzheimer's disease (AD). Several aspects of this neurodegenerative disease (i.e., largely sporadic incidence, increasing severity with age, proclivity for neuronal damage) mirror aspects of mitochondrial genetic disease. Until recently, though, it has not been possible to examine directly the mitochondrial DNA content of single neurons. This study has involved the application of a set of stains to identify neurons with either functional or non-functional mitochondrial electron transport chains (ETC, from which much of a neuron's energy currency [ATP] is generated), isolation of single neurons, and PCR (polymerase chain reaction)-based examinations of their mitochondrial DNA. The investigators found a low level of ETC-deficient neurons in the hippocampus, cortex and pontine midbrain. They have established conditions for post-staining single-neuron isolation, and the PCR studies have demonstrated the presence of mutated mitochondrial DNA in groups of isolated neurons. Additionally, a region of the hippocampal formation (the dentate gyrus) has been shown to be ETC-nonfunctional. To overcome certain limitations inherent in traditional PCR, the investigators have recently pioneered the application of a separate technique (rolling-circle amplification [RCA]) to amplify mitochondrial DNA prior to PCR. Using RCA followed by PCR, they will characterize the mitochondrial mutations on a per-neuron basis. (*Dr. Bennett can be reached at 434/924-8374; Dr. Miller can be reached at 434/924-9175*)

**VA Tech Toni Calasanti, Ph.D. (Department of Sociology) "Gender Differences in Informal Care Work for Persons with Alzheimer's Disease"**

This study explored the caregiving by husbands and wives of spouses with Alzheimer's disease and related dementias. Data were gathered through interviews with twenty-one caregivers and participant observation in support groups at multiple sites. Findings indicate that husbands and wives perform similar tasks for their spouses, and for similar reasons. However, two caregiving styles were evident. Men tend toward a more instrumental, problem-solving approach that focuses attention on accomplishing tasks, while women's more relational approach focuses attention on the care receivers as life partners. The instrumental approach allows caregivers to engage in emotional distancing; and men's lifelong experiences in mastering tasks and their more dominant positions in society allow them to manage their wives' disruptive and violent behavior, perhaps allowing them to keep their wives in their communities longer. For men, stress results when they become unable to assess problems and act accordingly. At these times, they have fewer personal resources for handling the stress. Women's relational approach, rooted in their caregiving experiences across the lifecourse, eases their gradual transitions into caring for spouses. However, their previous gender-based expectations of themselves lead women to feel more pressure to care for the "whole person," to smooth things over, and to maintain their husbands' happiness and dignity. For women, then, stress occurs when they are unable to keep themselves and their husbands on an even emotional keel and maintain their husbands' autonomy. These findings suggest that, rather than trying to see whether men or women experience the greater stress, research and interventions (such as support groups and educational materials) should focus on gender differences in styles and sources of stress and how to alleviate the latter. (*Dr. Calasanti can be reached at 540/231-8961*).

**VA Tech Shannon E. Jarrott, Ph.D. and P. Diane Relf, Ph.D. (Department of Human Development/Department of Horticulture) "Horticulture Therapy for Persons with Dementia: Replication of a Pilot Study"**

Horticulture therapy, which is the use of plant materials and gardening activities adapted to meet individualized needs and treatment goals, has been associated with increased activity, social interaction, concentration, and positive mood among persons with dementia in adult day services. This study compared the responses to horticultural programming of adults with dementia in institutional care settings to those of similar adults in more traditional dementia care programming (games, exercise, crafts), examining the behavioral and affective responses of individuals. Cognitive function scores indicated a moderate level of impairment on average. Both active and passive involvement were higher in the horticultural activities than during the traditional activities, with passive engagement being more common during the horticultural than the traditional activities. In contrast to previous research, exhibited affect in the two conditions was comparable, with interest being the most commonly observed emotion. One possible explanation is the approach and experience of the facilitator, new to the project, who was trained in horticultural therapy but had limited experience working with older adults with dementia. The findings raise questions about the extent to which an intervention depends on the nature and personality of the intervention facilitator and indicate a need to explore the effects of facilitator characteristics on participant experiences. (*Dr. Jarrott can be reached at 540/231-5434; Dr. Relf can be reached at 540/231-9279*)

**ODU Brian K. Payne, Ph.D. and Randy R. Gainey, Ph.D. (Department of Sociology and Criminal Justice) "The Social Context of Providing Care to Alzheimer's Patients: Specifying Interactions Between Social Disorganization, Service Utilization, Burden, and Mistreatment"**

Research suggests that individuals with Alzheimer's disease are at a higher risk of mistreatment and experts have attributed this high risk to the stresses that come with providing care to patients with Alzheimer's disease. In this study, the investigators examined whether neighborhood and city-wide factors contributed to caregiver burden potentially influencing mistreatment. Examining 750 case of elder mistreatment from three cities (Virginia Beach, Norfolk, and Chesapeake), we found that burden, as measured by the Virginia Uniform Assessment Instrument, was higher in Norfolk than in the other cities. In addition, burden had a stronger influence on serious elder abuse cases in more disadvantaged neighborhoods. The level of caregiver burden was the same in elder mistreatment cases, whether Alzheimer's or dementia were present or not. This suggests that the role of burden plays in explaining the mistreatment of patients with Alzheimer's disease may be overstated in past research. (*Dr. Payne can be reached at 757/683-3935; Dr. Gainey can be reached at 757/683-4794*)

#### **2003-2004 Awards Committee**

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Virginia Commonwealth University

## Virginia's Virtual Alzheimer's Center

Nico Stanculescu, Staff,

The Virginia Alzheimer's Disease and Related Disorders Commission

### The IDEA

When Dr. Zaven Khachaturian first shared his vision to create a Comprehensive Virtual Center on Alzheimer's Disease and Related Disorders with the members of the Virginia Alzheimer's Disease and Related Disorders Commission, the response was enthusiastic. Soon, however, the Commission members realized the multiple details of the complex task that stretched ahead of them. They would be required to construct something that had never been built before. In doing so, they would need to concentrate on the gestalt of the construction, beyond all walls, obstacles, or individual parts. They would need to think outside boundaries but within a huge universe of possibilities

But what exactly is this virtual center? Virginia's Comprehensive Virtual Center on Alzheimer's Disease is in the beginning stages of becoming a functional structure to support interrelated activities and initiatives on Alzheimer's disease and related disorders within the Commonwealth. Part of the beauty of this concept resides within its architecture, and more exactly in the blueprint of the virtual center. The mission here is to erect a most unique and efficient entity without walls though with all the functionality of a self-standing skyscraper overlooking the vast communities of Technology, Research, Education and Training, Information and Referral, Databases, and Services.

How will Virginia actually make this happen? How do we bring to life an idea in a virtual world and, yet, generate palpable solutions?

### The ARCHITECTURE

The Alzheimer's Commission has taken the notion of individuality and rethought it as the integration of all goals driven by a major need to reach out, treat and cure Alzheimer's disease. In other words, separate groups aim towards the same target: conquering this devastating disease. In many cases, however, things run parallel: groups don't know anything about each other's work or worse, about each other, their talents, resources or opinions. So, the underlying objective is to form effective partnerships among groups or organizations within the Commonwealth, to take advantage of their respective talents and resources and to advance the public health goals of the Commonwealth. Along with these partnerships, the virtual center intends to create a vibrant and open environment for discovery of knowledge by assembling a critical mass of talented and highly motivated professionals with different skills and perspectives. The operational keyword here is cross-discipline, where we aim to involve experts and professionals from different fields and/or institutions and invite them to work together on a common problem. The research philosophy is based on a systems approach to the solution of complex problems, where the emphasis is on building a multidisciplinary team of experts who individually have an in-depth knowledge of different parts of the problem. And so, the Comprehensive Virtual Center will serve as a facilitator or a spawning ground for new ideas and for solving specific problems. By establishing an efficient management organization, the Comprehensive Virtual Center expects to accelerate the process of discovering effective interventions and new methods of care aimed at reducing disability and extending independent functioning.

Virginia's Commission on Alzheimer's Disease and Related Disorders has formed several workgroups designed to:

- 1) address strategic problem areas as high priority targets in need of new initiatives and/or further development, and
- 2) help develop a strategic business plan for a virtual statewide Commonwealth of Virginia Comprehensive Alzheimer's Disease Center.

The Commission's workgroups are organized to identify some of the broadly defined generic challenges, problems, and opportunities related to capacity-building, services, social, financial, and scientific research issues that the Commonwealth must address in order to avert the pending public health catastrophe associated with the rapidly increasing numbers of people with Alzheimer's disease. The present roster of workgroups includes: Training and Education, Information and Referral, Research, Technology Transfer, Services (Diagnoses, Care, and Support), Databases, and Coordination (Figure 1).

**[CLICK HERE TO SEE FIGURE 1](#)**

The proposed virtual center, when fully established, will integrate, through its workgroups, all relevant programs, services and other bench-to-bedside activities to leverage as much added value as possible from what is already in place in the Commonwealth. The ultimate aim is to create a national resource that would be a magnet for major grants and contracts and the repository of additional research and development (R & D) resources generated by participating Virginia institutions from various outside sources.

### **The MODEL**

The Commission had the idea and had a goal, and now needed to detach from a two-dimensional concept (the blueprint) to a three-dimensional virtual model that would stand on the solid foundation envisioned for the center and would support interdependent partnerships and cross-disciplinary teams.

The solution came to the Commission as the members envisioned the cyclical operations of a restaurant (Figure 2). The kitchen provides the "focal point" or the laboratory, the place where the "product" is being experimented until ready to be then taken out into the dining room, where it is then served, "tested" and evaluated. The customers - in the dining room - provide immediate feedback to the kitchen staff and perhaps, propose new ideas and/or recipes. Also, the customer goes out into the community and spreads the word about the restaurant. And so, if the food and service are good, then more people will be attracted to the restaurant and better (and, hopefully, more innovative) meals will continue to be served.

Now, you will most likely ask, why think about restaurant operations when we deal with a virtual center on Alzheimer's disease? The answer lies within the very concept of our locus operandi, the virtual world. We operate in an unbound Universe of Solutions and some of the keys to our problems can be found outside the walls.

### **[CLICK HERE TO SEE FIGURE 2](#)**

By paralleling the restaurant-cycle concept, we have envisioned our center as a solid building with two main wings: PRIVATE and PUBLIC (Figure 3). The Private Wing is to be the "kitchen" or the "laboratory," the space where all seven workgroups of the center will meet, interact, work and generate ideas and proposals which are then filtered and prepared for presentation in the Public Wing. The Public side of the building represents the one opened to possible collaborators or partners, donors/sponsors, media, public-at-large, potential investors in projects proposed and/or initiated by the Center's workgroups. It is at this point where people will learn about the various initiatives within the Commonwealth, cross-disciplinary successes within research, services, education and training, information and referral programs, etc. On the other hand, by having this Public side, we can solicit and obtain pertinent criticism, inquiries, suggestions, support, which would then be submitted back to the "laboratory," in the Private side of our Center. And so a consistent cyclical communication would be built between the two "wings," as well as with the outside community, thus ensuring an ongoing fluency of the entire system.

### **[CLICK HERE TO SEE FIGURE 3](#)**

### **The CONSTRUCTION**

The actual construction site exists in the virtual world, at [www.alzpossible.org](http://www.alzpossible.org), where we currently have all of our "cranes" and workgroups up and running. In the next issue of Aging in Action, we will be introducing the mission and objectives as well as progress reports of each of the seven workgroups of the Virtual Center. Until then, we ask you to stay tuned and send us your questions or comments to [Janet.Honeycutt@vda.virginia.gov](mailto:Janet.Honeycutt@vda.virginia.gov)

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## **Calendar of Event**

### **November 19-23, 2004**

*Promoting the Health of an Aging Population.* The 57th Annual Scientific Meeting of The Gerontological Society of America to be held in Washington, DC. For more information call (202) 842-1275.

### **December 1, 2004**

*Annual Legislative Forum of the Virginia Elder Rights Coalition, 1:30 - 3:30pm* at St. Mary's Woods in Richmond. For more information, contact Joy Duke (804) 261-4046 or [joyduke@msn.com](mailto:joyduke@msn.com)

### **January 26, 2005**

Virginia Center on Aging's Annual Legislative Breakfast, St Paul's Church Parish Hall, Richmond. For information call (804) 828-1525.

**February 24-27, 2005**

*Careers in Aging*. 31st annual meeting and educational leadership conference presented by the Association for Gerontology in Higher Education to be held at the Renaissance Oklahoma City in Oklahoma City, OK. For more information go to [www.aghe.org](http://www.aghe.org)

**April 4-5, 2005**

*Joint Conference of the Virginia Guardianship Association and the Virginia Elder Rights Coalition*, Woodlands Hotel and Suites in Williamsburg. For more information, contact Joy Duke at (804) 261-4046 or [joyduke@msn.com](mailto:joyduke@msn.com)