Case Study

**Consumer-Directed Long Term Care Services**

by Martha Adams

Martha Adams is the Manager of Personal Assistance and Nursing Home Outreach Services for the Virginia Department of Rehabilitative Services, where she has worked for seven years. Prior to that she was Project Director for the Personal Assistance Services Project, Director of Community Education and Advocacy at the Endependence Center in Norfolk, and Medicaid Nursing Home Specialist at the Norfolk Division of Social Services.

“A Virginia plan to allow disabled and elderly Medicaid recipients to hire, train and supervise their own home-care aides is being hailed as progressive by advocates for the disabled and denounced as dangerous by advocates for the elderly.” Betty Booker, reporting in the Richmond Times Dispatch, January 13, 1997

**Objectives**

1. To describe the motivation of people with disabilities in pursuing consumer-directed home care services.
2. To explain the differences between existing publicly-funded home care services and the planned Consumer-Directed Medicaid Waiver.
3. To give readers an example of one recipient’s experiences.

**Background**

The proposed change in Medicaid home care policy, which would allow some service recipients the option of hiring home care workers independently, sparked much debate in the 1997 General Assembly. Virtually every legislator was contacted on the matter, both pro and con. Committee hearings on the matter were packed at 7:30 a.m. By the close of the General Assembly, a compromise budget amendment was in place that would limit initial participation in a Consumer-Directed Medicaid Waiver. Others will have to wait out completion of a regulatory process that will take an additional year or more.

As the debate over home care services ensued, observers questioned why the “elderly and disabled,” so commonly lumped together for housing, transportation, and other service development purposes, would publicly clash over a front burner issue for both groups - the availability and quality of home care services. The answer is both philosophical and practical.

Many people in the physical disability community - which is mainly people with disabilities themselves - are advocates of independent living. Simply put, this is the right to make personal life choices and assume the risks and responsibilities that go along with them. While basic to most of us, gaining this autonomy has been a hard-fought personal and political battle for others. Personal, in that families and well-meaning professionals tend to shelter children with disabilities, even when the “children” are grown. Political, in that our social system is not structured to anticipate or
welcome people with disabilities in the routine activities of school, work, recreation, or family life.

A friend who was paralyzed at age 19 described how he had to sue his loving mother/legal guardian in order to move out of a nursing home “against medical advice.” Doctors warned him that he would be dead within a year. That was 30 years ago and he has worked ever since, married, and been very active socially. Those 30 years have also involved daily battles for what should be very simple things, such as access to public streets via curb cuts and designated parking spaces that enable him to get out of his vehicle. As a user of personal assistance, he also wants to decide “who gets to see me naked.” This is simply a desire to control personal aspects of his life. The vigorous support of consumer-directed services by Virginia’s disability community epitomizes the philosophical and practical fight for very simple things.

The disability community has been very active in the development of consumer-directed personal assistance as an independent living service. Without this type of help, many people with severe physical disabilities and who are faced with serious medical problems, frequently wind up in hospitals and nursing homes. With some basic help, these same individuals can often lead independent lives.

The move toward consumer-directed programs is not just a Virginia trend. National independent living groups and aging organizations are increasing coordination efforts to expand consumer-directed services in several states. The National Council on the Aging and the World Institute on Disability jointly publish Consumer Choice News. The Robert Wood Johnson Foundation has recently funded several projects to expand consumer-directed options for older Americans. Florida is developing a “cash and counseling” model, targeting the frail elderly, that will give vouchers to a broker for purchase of services. There are clearly areas of common interest.

**Home Care Services in Virginia**

Virginia’s major public provider of home care services is the Elderly and Disabled Medicaid Waiver, which provided services to more than 10,000 Virginians at a cost of $74 million last year. Under the existing Waiver plan, applicants are evaluated based on functional, psychological, and medical needs. If the level of disability indicates that nursing home placement is imminent, many are offered home care as an alternative. The recipient or family member may then select a Medicaid-certified home care agency. The home care aides, who actually provide the services, are hired and scheduled by the agency under supervision of a nurse. The agency assumes all employer-related duties including assurance that aides have received basic certification, hiring and firing workers, directing the worker’s schedule, setting workers wages, and all other duties related to pay and taxes.

By comparison, Virginia’s Personal Assistance Services (PAS) Program, offered through the Department of Rehabilitative Services (DRS) and centers for independent living, is very small. In 1996, a total of 260 recipients were served with a total program budget of $1.8 million. There are approximately 300 on a waiting list at any given time, although people with the most serious needs, such as imminent nursing home placement, acute health problems, or job loss receive higher priority. Applicants are assessed to determine functional impairment, financial status, and ability/desire to assume responsibilities of a consumer-directed program. This evaluation is based on practical evidence of daily decision-making, short and long-range planning, the applicant’s awareness of his or her disability and any related health condition, the availability of a medical/social support network, and the applicant’s plans to
locate and hire a personal assistant. There is no restriction based solely on age, but only 20% of recipients are over 60.

Once eligibility factors are established and an application is approved, the recipient is awarded an individualized number of hours per week. The recipient may then select someone to work for him or her who is neither screened nor supervised by a third-party agency. The program does not require that assistants have training or certification, although most people working in the PAS Program do. If the recipient prefers to use a home care agency, they may, although they would be required to pay all costs above the current hourly rate for the PAS program. The recipient assumes several employer responsibilities: developing a service plan/contract with the assistant, scheduling the work hours, hiring and firing workers as needed, documenting worker citizenship and keeping time records that are submitted biweekly. In preparation for these responsibilities, the recipient receives an orientation at an independent living center that addresses program requirements and tips on recruitment, interviewing, and communicating his or her needs. This model is called consumer-directed, in that consumers of the service direct, or supervise, the assistants.

Offering Consumer-Directed Options Through The Elderly and Disabled Medicaid Waiver

In January, 1996, the General Assembly ordered the Department of Medical Assistance Services (DMAS) to develop a consumer-directed option for some recipients in the Elderly and Disabled Medicaid Waiver “with all due haste.” In response, DMAS sought passage of emergency regulations that would implement the program July, 1997. The perceived urgency was actually preceded by three years of study and one official DMAS report that indicated consumer-directed options were feasible and cost-effective, based on Virginia’s seven year experience and the impact of similar programs in other states. There was also mounting pressure from the disability community to act on recommendations, as opposed to studying the matter again.

The instant concern among elderly advocates and service providers was that the “frail elderly” would be forced to control their own care. There was equal concern that personal assistants would not be medically certified or supervised by a nurse. Compromise language ultimately stipulated that only people eligible to participate in the DRS PAS program, who also meet the criteria for the Elderly and Disabled Waiver, would be served initially. Development of final regulations for this option will take another year or more.

Clearly, not everyone with a disability, regardless of age, can manage their own assistants. Some disabilities, such as Alzheimer’s disease, involve dramatic changes in cognitive abilities. Those individuals would not have a consumer-directed option available. There are also people who demonstrate the ability to hire and manage assistants individually, but who simply do not want to assume that responsibility. Under Virginia’s Medicaid Waiver plan, they could select a home care agency for that purpose.

Services Under The Consumer-Directed Waiver

Unlike the DRS PAS Program, the Consumer-Directed Medicaid Waiver will require case management services for every recipient. DMAS will establish provider standards for Service Coordination Agencies (SCAs) that could be existing home care agencies, Area Agencies on Aging, independent living centers, or other organizations that meet the DMAS requirements. The SCA will develop the plan of care, offer case management, consumer training and support services, and will be reimbursed by DMAS as part of the service cost. The SCA will also be required to either have a nurse on staff, or demonstrate that a
nurse is available on a consulting basis to review medical issues. The recipient will then select workers of his or her choice and schedule them independently. If the recipient is not satisfied with this arrangement, he or she may opt to have services switched to a home care agency at any time.

These are the current plans which will become available to a small restricted group in July. As the final regulations weave through the administrative process, strong opinions on this matter are bound to resurface.

**Case Study**

Tom is 61 years old and has a progressive disability that causes increasing muscular weakness and frequent respiratory complications. The symptoms of this disability began when Tom was a young boy and gradually progressed throughout his life. His mother was very protective and skeptical of his activities based on his decreasing strength, but Tom surprised her - as well as doctors and other professionals - by completing college, holding several responsible jobs, and driving independently. Tom married in 1957 and had two children, now grown.

For many years, Tom relied on his wife to provide the physical assistance he needed with personal care. His motorized wheelchair, ramped entrances and home accessibility minimized his need for help beyond this. For many years, Tom was able to drive his lift-equipped van and was independent in transportation, although he is no longer able to drive. In 1990, the marriage ended and Tom was left physically, emotionally, and financially devastated.

Because of his Social Security and meager retirement income, Tom did not qualify for Medicaid services outside of a nursing home. Neither could he afford services privately after paying a mortgage, utilities, and medical costs. His only means of getting someone to help with personal care was to offer room and board in exchange for assistance. This led to a series of workers who were not as interested in providing his care as in finding a place to live. Consequently, Tom was frequently without help to even get out of bed.

Tom was found eligible for the DRS PAS Program in 1990 and was one of the first applicants accepted. The assessment recommended 36 hours per week of paid services, for which he pays $76 per month as copayment. He prefers someone to live in with him, which is not restricted by PAS, and Tom, because he actually hires the assistant who performs his care, finds the job performance is much better. His personal assistant helps him with getting in and out of bed, bathing, cooking, and housework. She also drives him to the store, church, or social events. Tom has also identified fill-in workers (who are paid within the allotted 36 hours per week), and they come in when the primary assistant is off-duty. He has extensive records on each worker, including detailed contracts that he files and updates on his computer.

Tom’s situation has not been perfect. He conducts extensive interviews and reference checks on each applicant, but several have not worked out and he has terminated their employment. His increased weakness has resulted in one serious fall while his assistant was out of the house and he summoned help with a life call button he wears. He was recently hospitalized with pneumonia and is receiving Medicare-funded home health services temporarily in addition to PAS, based on his medical needs. Tom’s susceptibility to respiratory infection is increasing due to his disability. He is still quite satisfied with the arrangement, however, because he is totally in charge of his help, his home, and his life.

Tom would meet Medicaid’s nursing home admissions criteria, and in the absence of PAS, he would be there now. He credits the ability to manage his own assistants for much of this independence. He does admit that he has become more forgetful over the years, but does not demonstrate any
cognitive limitations that have affected his ability to comply with all paperwork requirements, record keeping, or control of his circumstances.

Questions

1. Opponents of Consumer-Directed Medicaid Waiver Services argue that the aging process creates subtle changes in cognitive ability that might not be detected during an assessment for eligibility. When, and for what reason, should the state restrict the availability of consumer-directed home care services?

2. Many people over 60 pay privately for home care services and are free to hire someone of their choice. If services are paid through public funds, such as Medicaid, what other restrictions on consumer choice should apply?

Consumer-directed personal assistance for the disabled and the elderly has been a legislative issue in Virginia for at least the last few years. Advocates and professionals involved with these two communities (the disabled and the elderly), do not agree on all aspects of this important issue. On pages 10-12, we provide a brief background on its legislative history, and two editorials expressing different opinions on some of the issues raised in grappling with the complexities involved.

From the
Executive Director,
Virginia Geriatric Education Center

Iris A. Parham, Ph.D.

The VGEC and the Department of Gerontology have been in the usual mode of program presentation and project development. In May, there was a celebration in behalf of the graduates from the M.S. and Certificate in Aging Studies programs. This included a great group of students who completed the Certificate via video. This Certificate program has now happily graduated students from all areas of Virginia and many other states. Some pictures from our celebration are shown on page 17. For information on upcoming video courses listed elsewhere in this newsletter, call the VGEC or the Department of Gerontology.

In addition, the VGEC co-sponsored the 11th Annual Conference on Gerontological Nursing, May 20th, with the Virginia Nurses' Association Gerontological Professional Practice Council; the McGuire Veterans Affairs Medical Center's Nursing Services, Geriatrics and Extended Care; the Health Sciences Center at UVA; and VCU's School of Nursing. There were keynote presentations on managed care (Ms. Kathryn Beall, Bon Secours) and restraint reduction (Dr. Geri Hall, Department of Neurology, Mayo Clinic Scottsdale). The keynote on managed care was followed by a panel presentation moderated by Ms. Kathy Fletcher, UVA; Ms. Betty Cox, a critical care nurse; Ms. Ann Morris, IVNA; Ms. Phyllis Moore, Westminster Canterbury; Dr. Dave Perez, United Health Care; and Mr. Steve Gold, Vice President of Sentara Health System. There were afternoon sessions on healing touch (Ms. Denyse Brown) and skin care (Ms. Ann Donavan and Ms. Catherine Ratliff, UVA). There were about 80 participants, and the conference was highly rated.

Finally, the VGEC has recently completed the last ACR staff training for this year's contract with the Department of Social Services, on the topic of Managing Problem Behaviors in the Adult Care Setting.

Organization Updates

Age in Action regularly features "Organization Updates" and "Profiles on Professions." If you would like to submit information about your aging-related organization or individuals involved in the professional field of aging for publication in a future issue, please contact the Editor. The address, phone, fax number, and e-mail location can be found on the back cover.
From the 
**Director,**
**Virginia Center on Aging**

Edward F. Ansello, Ph.D.

It is appropriate, having recently celebrated Independence Day, that so much of this issue's contents revolve around independence in later life. Independence is, after all, the quintessential American value. We have included a key piece on personal assistance services (PAS) as modified by last General Assembly's HJR125; it contains four somewhat different perspectives on this one resolution intended to enhance the relative independence of individuals with compromised self-sufficiency. This issue also contains a report of Dr. Kirkpatrick's work on medication management in later life, more or less managing one's independence with the aid of geropharmacy. Medications are the most cost-effective modality for chronic care but come with a price tag of constant vigilance, i.e., ensuring nutritional adequacy and compliance with directions, while watching out for drug interactions and adverse drug reactions. In addition, this issue contains updates on Virginia's guardianship laws, provisions for citizens with adjudicated incapacity for self-care or independence. We invite our readers to think about these articles related to independence, and to send us their comments - independently or otherwise!

In a related vein, we would like to announce two forums scheduled for this October. It's not too early to put these on your personal calendars. The Professional/Consumer Advocacy Council (PCAC), of which VCoA is a member, is helping to co-sponsor a forum on "Consumer-Directed Care: What Does It Mean?" The host and chief sponsor is Insight Enterprises/ Peninsula Center for Independent Living. The forum will be held October 15, 1997 at the Holiday Inn in Hampton. Also, VCoA is co-sponsoring "The Social Security Summit," chaired by Senator John Warner, to be held at the Richmond Marriott on October 20, 1997. This will be an interactive conference with the Senator and a panel of national experts on Social Security in which the audience will examine the scope and direction of reform. Again, independence seems to be a thread through both of these conferences. For information on these events, call VCoA at (804) 828-1525.

**VCoA’s 20th Anniversary!**

In 1998, The Virginia Center on Aging will celebrate its 20th anniversary as a unique statewide resource on aging. If you have any photos, stories, or reminisces to share, please submit them to the editor of this newsletter for inclusion in a celebratory issue.

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

Thelma Bland, M.S.

As a practicing gerontologist and public administrator, I know for certain that change is the one variable that is constant in our chosen field of aging. As a department, VDA must prepare for the changing (and continuously evolving) role of the elderly in our society. We must deal with the changing demographics of aging. We must adapt to changing directions at the national, state, and local levels. We must meet the challenges that changing funding levels present to our operation and to the services and programs we finance. Although change presents challenges for us all, and we expend considerable energy resisting it, I go along with the recent television commercial that championed the notion that “change is good.” I believe that constant change keeps us on our toes and prevents us from becoming complacent.

VDA will be facing a significant change in the coming months. We will be moving our offices from our location at the corner of 7th and Franklin Streets in downtown Richmond to the Preston Building in the Koger Executive Center in Richmond’s west end. This move will mark the end of an era
for the department which has had its offices in a variety of locations in downtown Richmond since the 1970s. The benefits of moving to the west end, however, are many: not only is the rent less expensive, but our offices will now be convenient to out-of-town visitors because of our proximity to I-64, and we will have plenty of free parking adjacent to our building. We will also have a conference room that aging organizations and groups can use for meetings. Given the convenience of our new location, and the availability of free parking, we hope that organizations will take full advantage of this meeting space.

We are scheduled to be completely relocated by September 1st. The new phone number to reach the VDA is (804) 662-9333; our in-state toll free number remains the same: (800) 552-3402.

On a related note, let me recognize a coup for Virginia’s aging network. Virginia, and Virginia’s 25 Area Agencies on Aging, hosted the 22nd Annual Conference and Tradeshow of the National Association of Area Agencies on Aging (NAAAA). How does this relate to my thoughts about change? Simple: the topic of this year’s conference is “Riding the Waves of Change.” The NAAAA, representing more than 600 local Area Agencies on Aging from across the nation and its territories, held the conference at the Waterside Marriott and Convention Center in Norfolk in July. Over 1,000 individuals came to Virginia either as conference participants and their families, or as exhibitors. Workshops covered a variety of topics of interest to anyone who works in the field of aging, whether in a local Area Agency on Aging or other organization.

Thank you for helping to initiate change that improves the quality of life for older Virginians. This type of change is truly good!

**Focus on the Governor’s Advisory Board on Aging**

Suzanne S. Obenshain is the vice-chair of the Governor’s Advisory Board on Aging. The 23 members of this Board are appointed by the Governor and provide input to the Commissioner of the Virginia Department for the Aging. The current Board members were appointed by Governor Allen and come from a variety of backgrounds, represent a wide range of ages, and come from all regions of the Commonwealth. Suzanne was appointed to the Board in 1994 because of her knowledge of long-term care and her statewide involvement in the continuing care retirement community industry. She was elected by the Board to serve as their Vice-Chairman in 1995. Dr. Richard Lindsay, of the University of Virginia Health Care Center, is the Board’s Chairman.

Suzanne serves as a Board member for the Valley Program for Aging Services which serves a portion of the Shenandoah Valley within her own community. She has worked on several committees to promote aging and has helped to plan a number of aging events for the area. She served on an Elder Care Task Force formed in Harrisonburg to create an alliance among all organizations which serve the elderly in her community. She is a member of the Virginia Association of Nonprofit Homes for the Aging and has served on numerous committees, most recently the
Legislative Day committee.
In 1995, 6th District Congressman Bob Goodlatte selected Suzanne as the District’s Representative to the White House Conference on Aging. Although one of the youngest Delegates to represent Virginia, Goodlatte stated “she is genuinely concerned about and involved with issues affecting the elderly.” Suzanne was involved in several grassroots pre- and post-conference events. She worked closely with other Virginia Delegates as advocates for aging concerns today and into the 21st century.

Suzanne is a graduate of Virginia Tech and is a licensed Nursing Home Administrator with 7 fi years of experience at Sunnyside Presbyterian Retirement Community. Currently, she is taking a sabbatical from the nursing home industry to raise two small children but remains active promoting causes which affect Virginia’s elderly. She also consults with different organizations on long-term care issues. She lives with her husband Mark and their children in Harrisonburg.

Focus on the
Virginia Geriatric Education Center

Jennifer A. Worthington

Originally from Pennsylvania, Jennifer A. Worthington moved to Virginia to further her education. She attended and was graduated from the University of Richmond where she majored in psychology and minored in sociology. It was during her years at the University of Richmond that her interest in gerontology began and developed. Classes such as Social Gerontology; Dying, Death and Grief; and Psychology of Aging with a lab spurred her intellectual interest in the field of gerontology. Summer vacations in Pennsylvania found her employed in the housekeeping department of a continuing care retirement community. Her desire to work with and for the senior citizen population grew over four years and led her to pursue specialized training and education in gerontology. This desire was realized as she completed VCU’s Masters of Science degree in gerontology, concentrating in social services, in 1996.

Ms. Worthington joined the VGEC staff as a Program Coordinator in October. Her primary duties are associated with providing management and organizational support services for the Virginia Guardianship Association (VGA). The VGA seeks to strengthen guardianship and related services through networking, education, and tracking and commenting on legislation. Her responsibilities include producing the VGA quarterly newsletter, coordinating logistics for meetings and conferences, and processing new and renewal memberships; the office also serves as an information clearinghouse and a resource for association members as well as others interested in guardianship and related issues. For more information about the VGA call Jennifer in the VGA office, (804) 828-9622. She also provides support and assistance, as needed, to Lois Wyatt, Education Specialist/Program Director at the VGEC.

In addition to her work at the VGEC, Ms. Worthington also teaches a beginner’s aerobics class to active older adults at a local YMCA. Her special interests within the field of gerontology include wellness
issues, quality of life issues, and the impact of spirituality and religion on aging. Her interests outside of work include an active involvement in church and related activities, reading, playing sports, doing counted cross stitch, and spending time with friends.

Focus on the
Virginia Center on Aging

Mark Smith, MPA

Mark Smith’s relationship with the VCoA goes back to the 1993-94 session of the General Assembly when he assisted the Director and the Advisory Committee with maintaining stable funding levels for the Center. He is now one of the members of the Center’s University Council. This council, whose membership is drawn from the faculty and administration of Virginia Commonwealth University, serves to integrate the Center into the broader university community and to complement the guidance provided by the external Advisory Committee. Mr. Smith is the Director for Governmental and Community Relations, part of the Office of the Vice President for External Relations. In this capacity, he acts as liaison between the university and the Governor’s Office, the General Assembly, agencies of the Commonwealth, local boards of supervisors, and the Richmond City Council. He also monitors and analyzes government policies to determine their impact on academic programs, budget, or other university functions. His input in these areas is of great value to the Virginia Center on Aging.

Previously, he served at VCU as governmental relations assistant with responsibilities to plan and execute a comprehensive governmental relations program at the local, state and federal levels. He coordinated legislative efforts with VCU’s Health Science Campus, planned educational forums for university officials, and developed the university’s governmental relations communications plan.

Mr. Smith is an active member of the Richmond Jaycees and in that organization has served as a local and state officer and has received numerous civic service awards. He also is the Vice President and a member of the board of directors of the National Kidney Foundation of Virginia.

Mr. Smith graduated with honors from VCU’s Division of Administration of Justice and Public Safety with a minor in Political Science in 1980. He earned his Master of Science in Public Administration from VCU in 1994. He completed the Federal Executive Institute’s Work Team Development Program in 1989 and the Commonwealth Management Institute in 1987. He is a member of Pi Alpha Alpha, the National Honor Society for Public Affairs and Public Administration, and the National Honor Society of Phi Kappa Phi for scholastic achievement.

We have benefited greatly from our association with Mr. Smith and welcome him as a formal member of our University Council.

Notices of Events and Information of Interest to Professionals in the Field of Aging

If your agency or aging-related organization is sponsoring an event or has information to share with others in the field of aging, please submit your notice to the Editor of Age in Action for inclusion in our Calendar of Events or as a column in the newsletter.
Legislative History on the Issue of Consumer-Directed Personal Assistance Services

by Michael Hite

In 1995, the Virginia General Assembly approved House Joint Resolution (HJR) 539 requesting the Department of Medical Assistance Services (DMAS) “to evaluate the feasibility and advisability of amending the Elderly and Disabled Waiver to allow individuals to hire their own personal attendants.” DMAS reported its assessment and recommendations in *A Study of Consumer Directed Services* (House Document No. 18, 1996).

Based on these recommendations, the General Assembly passed HJR 125 in 1996 directing DMAS “with all due haste” to “request a waiver or a waiver amendment from the federal government and implement with all due haste consumer-directed personal assistance services, in conjunction with the agency-directed model currently available, to Virginians who are elderly or who have disabilities.”

In *Medicaid-Funded Consumer-Directed Personal Assistance Services* (House Document No. 22, 1997), DMAS, in response to HJR 125, proposed a model for allowing “consumers to hire their own personal attendant after demonstrating their ability to manage and supervise the performance of that attendant.” Subsequent to this report, the General Assembly (1997 Virginia Acts of Assembly, Chapter 924, Item 322.D.6) directed DMAS to “promulgate regulations, to be effective July 1, 1997, to implement consumer-driven personal assistance services to Virginians who are eligible to participate in the Department of Rehabilitative Services’ personal assistance program and who are determined to be at-risk of nursing home placement in the near future.” The proposed regulations have just been released in the *Virginia Register of Regulations* dated July 21, 1997 (pages 2851-2862). DMAS is requesting that the Governor approve its adoption of the emergency regulations to allow it “to implement another service delivery method as an option to long-term care community based services.” The agency notes that “although the emergency regulatory process does not have a specified formal period of public comment, DMAS has demonstrated a willingness to and will continue to entertain input from all interested parties.”

Single copies of House Document No. 18 (1996) and House Document No. 22 (1997) can be obtained from the General Assembly’s Legislative Bill Room in Richmond [(804) 786-6984].

*EDITORIAL:*

The *Virginia Coalition for the Aging* (VCA) on Consumer-Directed Personal Assistance Services: An Issue in the 1997 Session of the Virginia General Assembly

by Mary Ellen Cox, Chair, VCA and Betty J. Reams, M.S., VCA Legislative Coordinator

The 1997 session of the Virginia General Assembly saw some lively action on several fronts. One such confrontation was over the issue of promulgating emergency regulations for consumer-directed personal assistance services for persons with disabilities. The actual legislation was passed in a previous session. The 1997 amendment to the budget bill simply stated that emergency regulations would be adopted so that the program could be implemented to all qualified persons within a very short time frame.

While original passage of the former amendment created hardly a stir, this amendment raised concern among several groups, especially the elderly. The opposition came mostly from advocates and home health organizations. They shared concerns for older Virginians and persons with disabilities...
who were cognitively impaired. There appeared to be a lack of clearly defined regulations which could provide protection for this most vulnerable segment of our citizenry. It was thought that persons with impaired cognitive functions could be unduly exposed to the potential of neglect, exploitation, or abuse.

This major concern over the issue of cognitive impairment versus physical disabilities was discussed at length, even to the point of recommending an age limitation for participation. Aging advocates felt that any age-related parameters would be blatant age discrimination. Almost all interested parties worked together to influence final passage of legislation that would offer something for everyone involved. As always, not everyone was completely satisfied, but the compromise position prevailed.

There were some who opposed outrightly the enactment of any regulations that would add to the population being served by the consumer-directed personal assistance services program, but most were opposed only to the rapid pace of enactment. The latter called for the process to be slowed down, no emergency passage, but allowing for public input and responses that would implement safeguards for persons who would be eligible and accepted into the program.

Several legislators were in support of killing the entire legislative piece and denying the services to everyone until better guidelines and regulations were in place. However, there were moderating voices that advocated the best of both worlds - continue the program for those already served through the current program at the Department of Rehabilitative Services, but not add any new persons to the eligibility categories until the full regulatory process was followed.

The Virginia Coalition for the Aging strongly supported this compromise action and so indicated to legislators and others that this position seemed to serve the best interest of most Virginians. Consumer-directed personal assistance services has provided opportunities for greater independence for persons with disabilities. It has provided flexibility in hiring an assistant who could respond when the need was there and not be tied to a schedule that was for the convenience of an agency. It promoted more responsibility for any person needing the service as well as promoting self-esteem through control over personal schedules. Agency-directed services have been available for a long time and this was an additional effort to expand a working program into the arena of more freedom and greater control by the recipient.

The General Assembly did pass legislation indicating the following: (HB 1600, Item 322.D.6) "The Department [Department of Medical Assistance Services] shall follow the procedures of Article 2 of the Administration Process Act as set forth in Section 9-6.14:7.1, Code of Virginia, in promulgating regulations to implement these services for other Virginians who may be eligible for the program."

The full regulatory process will allow time for input and the opportunity to add appropriate safeguards. This should be a giant step toward assuring that all Virginians, persons who are older and persons with disabilities, have the fullest protection when participating in this very worthwhile and needed program.

See you next year for a continuation of this issue if the regulatory process does not generate regulations that address concerns of major advocates!

EDITORIAL: Who Could Be Against More Care Options?

by Bryan Lacy

While the above title makes my biases clear on HJR 125, some background will make clear why I have this bias. My perspective may be somewhat unique because not only have I been a recipient of BOTH consumer-directed personal assistance services and agency-directed
personal care for 13 years, I have also been in a position to have played a role in the policy development in both of these areas. For instance, I was a member of the [1995] HJR 539 Work Group, the predecessor to 1996’s HJR 125.

What is amazing about some of the rhetoric of some of the opponents of HJR 125 is that all we are talking about is creating more options for those people who are capable of self-directed care. No one would be forced to select this option. Each applicant would continue to be evaluated on a regular basis using the Uniform Assessment Instrument [UAI]. The UAI has many questions designed to evaluate mental status. Those folks who were found to have problems in this area will simply not be eligible for this option.

Some home care agencies make quite a point about there not being any back-up system in the consumer-directed model. This is an area that needs addressing and is in the process of being addressed by the Personal Assistance Services [PAS] Program. But the agencies' position here is like the pot calling the kettle black. True, some agencies have "floating" back-up assistants during weekdays. This is definitely not the case on Saturdays, which is when I depend on an agency. Apparently very few agencies actually make any provision for back-up during these times.

Loyalty to the consumer is often enhanced through the PAS model. Agency aides tend to have a fairly rapid turnover rate. With a few notable exceptions, in my experience most are either unwilling or unable to make a long-term commitment to a specific client. (The exceptions end up becoming very much like a "PAS model" assistant.) This can potentially have an adverse impact on both quality and continuity of care. Compare this with the two personal assistants I have now. One has been with me well over two years. The other one, who assists me in my office two days a week, has been doing so for 14 years!

Again, the consumer-directed model is NOT for everyone. For people who are either very acutely ill and/or medically unstable, this would probably not be a good option. We can hope that agencies would reserve their best assistants for these cases. For the rest of the eligible population however, why not increase the available options?

Consumer-Directed Care: What Does It Mean? Who’s Doing It? What Are The Implications For Quality Care in Virginia?

Both professionals and consumers are invited to attend a one-day workshop on October 15, 1997, from 9:30-3:00 at the Hampton Holiday Inn, 1815 W. Mercury Blvd., Hampton. The purpose of the event is to provide information, share various perspectives and promote discussion of Virginia’s recently approved Medicaid Waiver to expand home care services that are not medically managed. This workshop is co-sponsored by the Professional/Consumer Advocacy Council, Virginia Center on Aging, and the Peninsula Center for Independent Living/Insight Enterprises. There is no fee for attendance. Lunch is on your own. If you are interested in receiving a copy of the agenda, or have additional questions, please contact Donald Fennell at (757) 827-0275.

Note to Readers

If you are interested in learning more about consumer-directed services, you can request copies of the relevant legislation and reports from the Virginia General Assembly. Also please attend the workshop being offered in Hampton in October (see above). As always, Age in Action invites your letters and comments on this issue and other features in the newsletter. See the back page for submission information.
New Guardian of Last Resort Program Begins this Summer

by Bill Peterson

In May, the Virginia Department for the Aging, in cooperation with the Virginia Guardianship Association (VGA), issued a Request for Proposals (RFP) to solicit proposals from agencies and organizations in rural communities throughout Virginia to develop and implement a Guardianship of Last Resort Program (GOLR). The RFP was part of an ongoing effort by VGA and the General Assembly to identify cost-effective alternatives to the local Sheriff as the guardian of last resort in those situations where there are no family or friends to act as guardian or where there is insufficient income to pay an attorney to act as the guardian. After proposal review in June, the Tazewell County Department of Social Services was chosen to receive funding during the 1997-98 state fiscal year. It proposes to develop and implement an independent, volunteer-based GOLR program governed by a Citizen Oversight Board.

In 1993, the VGA approached the General Assembly with specific concerns about the role of the Sheriff as the guardian of last resort and the lack of available guardians to serve indigent wards. As a result, in 1995 the General Assembly authorized start-up funding to be funneled through the Virginia Department for the Aging to examine models of providing guardianship services that could replace the Sheriff as the guardian of last resort. Changes to Virginia’s guardianship laws were also made during the 1997 session of the General Assembly (see page 11 in the Spring, 1997 issue of Age in Action). These changes will eliminate the court’s option of appointing the Sheriff to act as the guardian of last resort beginning in 1999. In many cases, the local Sheriff’s Office has neither the time, training, nor additional staff to handle the type of complex guardianship cases that are assigned by the courts. Although some Sheriffs have done an excellent job of acting as guardians, many others have indicated that the law enforcement demands of their office leave little time for them to take on these cases.

In lieu of the Sheriff as the guardian of last resort, the Commonwealth is seeking alternative programs for assuring that a qualified guardian or conservator is available to all persons who are adjudicated to be incapacitated. Although the Sheriff may soon no longer be appointed as the guardian of last resort, the need for qualified guardians and/or conservators to meet the needs of Virginia’s many indigent persons is growing. A 1988 study of guardianship in Virginia identified more than 2,000 adults in need of guardianship services. In fiscal year 1993-1994, Virginia’s local departments of social services reported that one-half of those persons determined through Adult Protective Services (APS) investigations to need guardians did not have a responsible person available to serve in this role.

Two GOLR program models are currently receiving funding through the General Assembly: a paid guardian model operated by the Personal Support Network of Falls Church and a volunteer guardian model operated by the Chesapeake Department of Social Services in Chesapeake. (See our Fall, 1996 and Winter, 1997 issues.) The Commonwealth has now expanded the GOLR program concept to a third community in a rural area, Tazewell County. For more information about any of the GOLR programs operating in Virginia, please contact Bill Peterson at the Department for the Aging: (804) 662-9325.

Correction
In our last issue, in the Summary of the Major Provisions of the New Guardianship Bill (page 11), it was noted that SB 408 would take effect on July 1, 1997. This is incorrect. The mandates in the bill will not take effect until January 1, 1998, and the specific mandate which relieves the local Sheriff from being appointed by the court as the guardian of last resort will not go into effect until January 1, 1999.
A Task Analysis of Medication Management in Adult Care Residences and the Implications for Policy

by Mary Ann F. Kirkpatrick, Ph.D.

For her doctoral dissertation, Mary Ann F. Kirkpatrick, studied the handling of medications in adult care residences (ACRs) in Virginia. The best way to accomplish this goal, was to visit ACRs and observe medication aides actually assisting residents with their drugs. Between January 4 and March 2, 1997, Dr. Kirkpatrick visited a total of 60 ACRs which primarily serve elderly persons. She observed sixty medication aides assisting with the administration of 911 medications for 266 residents.

When discrepancies were observed between actual task performance and desired task performance, as described in the Virginia Medication Management Training course or in the Virginia Department of Social Services regulations, Dr. Kirkpatrick attempted to determine which barriers might be responsible for these discrepancies. Of the 353 discrepancies observed, none were thought to be due to a functional (educational or cognitive) deficit and only a small number were due to inadequate training. Most discrepancies were due to management problems or deficits. The management deficits were categorized as "proper performance punishing," "non-performance rewarding," "does not matter," or "obstacles." Dr. Kirkpatrick found differences in the types of discrepancies observed by ACR size and by medication aide training level. She also found a difference in the types of discrepancies observed and the location (rural or urban) of the ACR. A majority of errors observed in medium and large ACRs were attributed to proper performance being punished or non-performance being rewarded. This was also true in urban ACRs. Errors observed in rural and small ACRs were more often categorized as "does not matter" because there were no consequences, favorable or unfavorable, to task performance. Licensed practical nurses had the highest error rate per person. This rate appeared to be related more to the LPNs status as owners of ACRs than to their training level.

The error observed most often was touching tablets and capsules. Aides touched medicines dispensed in standard vials as well as those dispensed in bubble packs. Most aides indicated that they touched tablets and capsules to avoid having the medicine fall on the floor. Other errors observed included not drawing back on a syringe plunger to ensure the needle was not in a vein prior to injecting insulin, not waiting at least five minutes between the instillation of two eye drops, and not wearing gloves when administering eye drops or when giving insulin.

Results of this study support the employment of non-licensed staff trained with the Virginia Medication Management Training course to assist with medications in ACRs. Study findings also suggest that the Virginia Medication Management Training course is an effective means of teaching medication management task performance.

The Virginia Geriatric Education Center (VGEC) has been involved with the Virginia Medication Management Training course since its inception. Dr. Kirkpatrick co-authored the program in 1991 as a master's student in gerontology at VCU. In July 1996, the VGEC contracted with the Virginia Department of Social Services (DSS) to maintain records for the Virginia Medication Management Training program and to provide training for ACRs. The VGEC, in cooperation with the DSS, has also formed an ACR Advisory Board to monitor training needs for Virginia ACRs.
Scholarship Competition for Gerontology Students

The Virginia Association on Aging (VAA) is pleased to announce the 1997 Outstanding Gerontology Student Scholarship Competition. A scholarship of $1,000 will be awarded to a full-time graduate student who demonstrates commitment to the field of aging through the following: 1) academic excellence as evidenced by transcripts, academic honors received, and membership in honorary societies; 2) research projects; 3) work experience and career plans; 4) community service and volunteer activities; and 5) faculty recommendations. The successful applicant must be enrolled as a full-time student in a curriculum involving aging studies (behavioral, social, or health sciences; policy or religious studies; humanities; planning; or practice). For application and additional information, write to: Lora Hamp, Virginia Geriatric Education Center, P.O. Box 980228, Richmond, VA 23298-0228 (Attn: Scholarship Committee). The deadline for applications is November 1, 1997.

Video Courses in Gerontology

The Virginia Geriatric Education Center (VGEC) at Virginia Commonwealth University is offering two video courses during the Fall, 1997 semester: Gerontology 601, The Biology of Aging; and Gerontology 602, The Psychology of Aging. For more information or to register for these courses, please contact Michelle Utterback or Lois Wyatt in the VGEC at (804) 828-9060.

Gerontology Courses at Virginia Commonwealth University

For the Fall, 1997 semester, the VCU Gerontology Department will offer Introduction to Gerontology, Physiological Aging, Psychology of Aging, Social Gerontology, Aging and Human Values, Field Studies in Gerontology, Aging Mental Disorders, Practicum: Geropsychology, and Independent Study. For more information regarding these courses, please contact Kathy Rocker in the Gerontology Department at (804) 828-1565.

The Post-Baccalaureate Certificate Program at Virginia Tech: Administration of Community Based Services for Older Adults

Virginia Tech, through its Center for Gerontology, offers a Post-Baccalaureate Certificate in the Administration of Community Based Services for Older Adults. This program is designed to prepare individuals from multiple disciplines for careers in the administration of community based programs and services. The certificate program provides persons with a competitive edge for career and job mobility by adding gerontology and administration coursework to their prior education and career experiences. Students may enroll in the certificate program as either non-degree or degree seeking students. Certificate students must complete 24-25 credits of coursework in gerontology and administration. The program is offered on the Blacksburg campus as well as at Tech’s Northern Virginia Center. For more information, contact the Center for Gerontology, 237 Wallace Hall, Virginia Tech, Blacksburg, VA 24061-0426; (540) 231-7657.
The First Gerontology Scholarship Endowment Auction

On September 13, 1997, the Gerontology Alumni Association (GAA) of Virginia Commonwealth University will sponsor its first auction. The purpose of the auction is to raise enough money to establish a scholarship endowment fund for students pursuing either the Master of Science degree in Gerontology or the postgraduate Certificate in Aging Studies at Virginia Commonwealth University. The auction will be held at the Hyatt Richmond, 6624 W. Broad Street, from 3:00 until 7:00 p.m. A silent auction and social will be followed by a live auction. Visit the GAA web site (http://views.vcu.edu/sahp/gerontology/alumnigr.htm) for a weekly updated listing of auction items and donors.

The auction offers an excellent opportunity to interact with professionals in the field of aging and to support students pursuing careers in gerontology. The $25.00 admission will cover the cost of hors d'oeuvres, wine, entertainment, and door prizes. The admission cost is partially tax-deductible.

The School of Allied Health Professions at Virginia Commonwealth University is co-sponsoring the auction. If you or your organization would like to donate a new item or underwrite some portion or all of the auction cost, please contact Stephen C. Harvey, Assistant Dean, School of Allied Health Professions by e-mail: scharvey@gems.vcu.edu, or at (804) 828-7247. To reserve tickets for the auction complete and mail the registration form below. If space is available, tickets can be purchased at the door.

Gerontology Endowment Auction Registration Form
September 13, 1997, Hyatt Richmond, 6624 W. Broad Street
Send in your registration by Aug 20 and be eligible for Special Door Prizes!

Name/Title: ____________________________________________

Number of Tickets ($25.00 ea.): __________________________

Address: ______________________________________________

City/State/Zip: _________________________________________

Phone: __________________ FAX: __________________ E-mail: __________________

Method of Payment (check box):
☐ Check or money order enclosed
☐ Credit Card - Type: ☐ Visa ☐ MasterCard ☐ Discover

Card No: ______________________________________________ Exp. Date: __________

Amount $: __________________ Cardholder's Signature*: __________________

Make check payable to Gerontology Alumni Endowment Auction. Mail payment and completed registration form to Department of Gerontology ATTN: GAA, Virginia Commonwealth University, Box 980228, Richmond, VA. 23298-0228.

*My signature authorizes Virginia Commonwealth University to charge my credit card in the above amount.
On May 17, 1997, the Department of Gerontology at Virginia Commonwealth University invited its faculty, staff, alumni, students, and their friends and family to celebrate its graduating class. The event, held at the Omni Hotel in Richmond, was attended by 30 people. Congratulations were extended to graduates in the M.S. and Ph.D programs, as well as students in the residential and distance-learning Certificate in Aging Studies program. All of us extend our welcomes to our new professional colleagues in the field of aging.

Top row (l to r): Lois Wyatt, Myra Owens, Dr. Nancy Osgood, Dr. Iris Parham (Dept. Chair), Dr. Linda Daugherty, Dr. James Cotter. Bottom row: Cathy Saunders, and five new graduates: Fern Alderfer, Emily King, Jackie Creech, Lora Flatlum-Hamp, and Kimberly Brill.

Right: Dr. Linda Daughert speaks with a luncheon guest.

Above: Dr. Iris Parham congratulates new graduate Lora Flatlum-Hamp.

Right: Myra Owens and Lois Wyatt, two Gerontology alumni, are deep in discussion.
Calendar of Events

August 25-28, 1997
"The 1997 Florida Aging Network Training Conference,"
The Florida Council on Aging, Trade Winds Resort, St. Petersburg Beach, FL. For further information, call (904) 222-8877.

September, 13, 1997
The Gerontology Alumni Association of Virginia Commonwealth University is sponsoring a silent auction and social to benefit a scholarship endowment fund. Everyone is invited! 3:00 pm - 7:00 pm at the Hyatt Richmond at 6624 W. Broad St. See page 16 for details.

September 18-19, 1997
"Nutrition and Aging XII: Malnutrition in the Elderly,"
John L. McClellan Memorial Veterans Hospital and the University of Arkansas for Medical Sciences. Excelsior Hotel, Little Rock, Arkansas. For more information, call (501) 661-7962.

September 24-26, 1997
"Successful Aging and the New Millenium: Will the Promise be Realized?" Rochester Conference on Health, University of Rochester Medical Center. Hyatt Regency Rochester, New York. For more information, call (716) 275-4392.

October 15, 1997
"Consumer-Directed Care: What Does It Mean? Who's Doing It? What Are The Implications For Quality Care In Virginia?" Co-sponsored by the Professional/Consumer Advocacy Council, the Virginia Center on Aging, and the Peninsula Center for Independent Living/Insight Enterprises.
Hampton Holiday Inn, 9:30 am - 3:00 pm. See page 12 for details.

October 20, 1997

Cancelled
Governor’s Conference on Aging Regional Forums scheduled for November and December, 1997. For information, contact Bill Peterson at the Virginia Department for the Aging at (804) 662-9325.

Visit us on the WorldWideWeb!
Many agencies, departments, and organizations maintain home pages on the worldwide web. These sites contain information about services, resources, research, academic programs, and much more of interest to professionals and others in the field of aging. The sponsors of this newsletter can now be found on the Web. If you have computer access, we recommend a visit to these sites:

Virginia Center on Aging: http://views.vcu.edu/vcoa
Virginia Geriatric Education Center: http://views.vcu.edu/sahp/gerontology/vgec.htm
Virginia Department for the Aging: http://www.aging.state.va.us

From these sites, you can link to many others of organizations doing related work.
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804/828-1565.
Alzheimer’s Research Award Fund Recipients Announced

The Alzheimer’s and Related Diseases Research Award Fund (ARDRAF) was established in 1982 to provide small grants to scientists in Virginia to promote research into Alzheimer’s disease in a wide variety of areas, for example, the causes, epidemiology, diagnosis, and treatment of the disorder; public policy and financing care; and the social and psychological impact of the disease upon the individual, family, and community. ARDRAF is administered by the Virginia Center on Aging at Virginia Commonwealth University. The four grant recipients from the 1997-98 round of awards are as follows:

“Mechanism for Memory Impairment and Pathophysiology Associated with Aging and Alzheimer’s Disease,” Thomas C. Foster, Ph.D., University of Virginia.


“Does Estrogen Protect Basal Forebrain Neurons from Neurodegenerative Changes?” Francis J. Liuzzi, Ph.D., Eastern Virginia Medical School.

“Cytochrome Oxidase Associated Pathophysiology in Alzheimer’s Disease,” Russell H. Swerdlow, M.D., University of Virginia.

To receive summaries of these proposals or to be placed on the mailing list to receive information for next year’s award cycle, please contact Constance L. Coole, Ph.D., Virginia Center on Aging, P.O. Box 980229, Richmond, VA 23298-0229, call (804) 828-1525, or e-mail to ccoole@gems.vcu.edu.

Responses to case studies and comments on other newsletter features are invited and may be published in a future issue. Please include your name, title, institution, and signature. Mail comments to: Michael P. Hite, Age in Action, P.O. Box 980229, Richmond, VA 23298-0229, 804/828-1525, fax to 804/828-7905, or e-mail to mhite@gems.vcu.edu.

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