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#### **ABSTRACT**

This Replication Plan describes an Administration on Aging funded Project, "Assisting Caregivers of Black and Rural Elders with Dementia: Progressive Training through Trusted Resources." The project directly developed the capacities of trusted community leaders (n=69) who served as trainers of African American and rural family caregivers (n=200) in Central and Southside Virginia. The project indirectly improved the capacities of caregivers through the conduct of workshops, and subsequently increased the ability of elders with dementia to remain, as appropriate, in their communities and avoid premature institutionalization. A proven model, this project has been used by the Administration on Aging at national and regional meetings to demonstrate its effectiveness as an educational delivery system. The primary products from this project were a substantive training manual ("Families Who Care: Assisting African American and Rural Family Caregivers Dealing with Dementia" (RC020823)); two directories of helpful resources -- one with national resources, and the other, Virginia resources; this Replication Plan; and a Final Report to the Administration on Aging (RC020822). The pilot project officially ended August 30, 1994, but its benefits will continue to be felt via the community leaders who have been empowered to help those in their communities through linkages with their local chapters of the Alzheimer's Association and other community based resources. (AA/Author)

# **Families** Who Care

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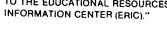


# Replication Plan

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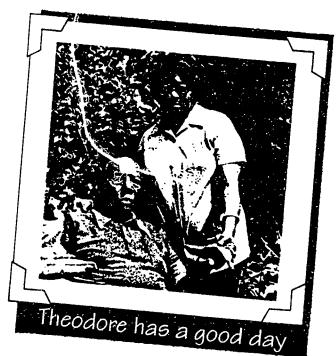
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RC 020824

# Families Who Care: Assisting African American and Rural Caregivers Dealing with Dementia

A Replication Plan

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# Families Who Care: Assisting African American and Rural Family Caregivers Dealing with Dementia

### A Replication Plan

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#### **ABSTRACT**

This Replication Plan describes an Administration on Aging funded Project, "Assisting Caregivers of Black and Rural Elders with Dementia: Progressive Training through Trusted Resources," (grant no. 90-AT-0525) awarded to Virginia Commonwealth University, the Virginia Center on Aging, Constance L. Coogle and Ruth B. Finley, Co-directors, in cooperation with the Virginia Geriatric Education Center. It was essentially a "train-the-trainer" grant in which "trusted community resources" -- health care professionals, social workers, teachers, ministers, etc. -- were trained by staff (first level training) and who then recruited and trained African American and/or rural family caregivers dealing with dementia. A proven model, this project has been used by the Administration on Aging (AoA) at national and regional meetings to demonstrate its effectiveness as an educational delivery system.

The primary products from this project were a substantive training manual (Families Who Care: Assisting African American and Rural Family Caregivers Dealing with Dementia); two directories of helpful resources -- one with national resources, and the other, Virginia ones; this Replication Plan; and a Final Report to the Administration on Aging. (An order form is in the back of this publication). Sixty-nine "trusted community resources" were trained and in turn trained approximately 200 African American and/or rural family caregivers in Central and Southside Virginia. The pilot project officially ended August 30, 1994, but its benefits will continue to be felt via the community leaders who have been empowered to help those in their communities through linkages with their local chapters of the Alzheimer's Association and other community based resources.



#### About the Virginia Project

The operational focus of the Virginia Center on Aging (VCoA), a state agency, is applied gerontology, i.e., the translation of research to benefit real practice. Ongoing research and education emphases include: community-based supports in aging; multidisciplinary health care; and disabilities in aging, both lifelong (developmental) and late-onset. Consistent with these activities, the VCoA obtained funding from the U. S. Administration on Aging to pursue the project, "Assisting Caregivers of African-American and/or Rural Elders With Dementia: Progressive Training Through Trusted Resources." In cooperation with the Virginia Geriatric Education Center, the project became a guide and resource tool for training caregivers. The project aimed to identify rural and/or minority family members providing care for elders with dementia, and help them provide better care. In this way, the project hoped to improve eldercare services for rural and minority (primarily African American) elders with dementia in Central and Southside Virginia, the areas of the state targeted for the innovative project.

In the territory covered by the Alzheimer's Association - Greater Richmond Chapter (24 counties and 5 cities), there are approximately 18,000 persons with Alzheimer's Disease. The territory defined by the Southside Chapter (8 counties and 3 cities) has an estimated 4,080 people with AD. When taken together, these persons comprise about 22-25% of the state's estimated 88-100,000 persons with AD. Since four family members, on the average, are involved to some extent in caring for loved ones with AD, the number of Virginians affected by AD is much larger. African American and rural families were targeted by this project since they tend to under-utilize community services.

The project formed key partnerships with state and local agencies and other communities (such as faith communities) concerned with helping older Americans lead healthier lives. There were two groups of these partners, called Regional Needs and Resources Teams, one in Central Virginia, and the other in Southside. The most relevant and significant organizations that might address the continuing needs of African American and rural caregivers of elders with dementia were represented on these Regional Teams. The Teams advised project staff concerning the educational needs of caregivers and resources available in the targeted regions. Members of these teams provided continual guidance and assistance in the development of the training manual to assure that it was culturally sensitive and specific to the needs of the target populations. Key members from each Regional Team contributed Educational Chapters and Caregiver Lesson Plans. The Regional Needs and Resources Teams were also instrumental in the recruitment of potential trainers and caregiver participants.

An important part of this effort focused on the specific needs of minority and rural caregivers who may not have previously taken advantage of community resources for a variety of reasons. The Chapters on ethnic competence and rural considerations, as well as the Module on Formal Supports and Resources, were specifically designed to encourage the use of community services by minority and rural caregivers of older adults with dementia. The project also produced national, state, and local (Central and Southside Virginia) resource directories on diskette for trainers and others involved in assisting caregivers. (The National and Virginia State directories are available on diskette from the editors. See Order Form in back of manual.) In addition, caregiver participants were provided with an abbreviated directory of resources available



in their own communities to encourage their utilization of formal services.

By reinforcing the basic family infrastructure and recognizing the desire for self-reliance, the project increased awareness of community services, decreased distrust of service providers, and improved caregiver knowledge and skills. The specific objectives and outcomes of the project are outlined below.

Objective I: To form a partnership of the most relevant and significant organizations that might address the continuing needs of Black and rural caregivers of elders with dementia, to be called Regional Needs and Resources Teams (RNRTs).

- 1. Regional Teams in Central and Southside Virginia were established and advised project staff concerning the educational needs of caregivers and resources available in the targeted regions. Members of these teams provided continual guidance and assistance in the development of the training manual, and recruitment of potential trainers.
- 2. Key members from each Regional Team reviewed the training manual to assure that it was culturally sensitive and specific to the needs of the target populations. Some of the members contributed modules to the manual, and others served as trainers of caregivers. RNRT members were especially helpful in recruiting both trainers and caregivers.

Objective II: To develop a comprehensive, culturally sensitive training package targeted to caregivers of elders with dementia that is organized according to the progression of cognitive, social, and behavioral impairment.

- 1. The training package consisted of a training manual, resource materials used during the two-day training sessions, a suggested reading list, and Caregiver Resource Directories with listings particular to the targeted localities in Central and Southside Virginia.
- 2. The training manual explains in detail, exactly how to recruit caregivers, find a meeting site, and publicize the workshops. It provides step-by-step instruction on how to conduct caregiver workshops, and a Chapter on adult learning theory. There are 19 Caregiver Lesson Plans (modules), as well as evaluation instruments, and supplementary reading and reference lists for advanced preparation. Special Chapters on cultural sensitivity and outreach to African American and rural populations are included.

Objective III: To implement and test the "train-the-trainer" model as a mechanism for caregiver education.

1. The train-the-trainer approach was applied at the local community level to effect a large-scale increase in expertise and knowledge. Caregivers became more knowledgeable about dementia and available community resources, resulting in improved quality of life for caregiving families.



2. The project sought trainers of caregivers who were:

- (1) Knowledgeable of caregiver issues, especially caregiving for dementia victims,
- (2) In touch with caregiver networks locally (Area Agencies on Aging, Social Services, local Long Term Care Coordinating Committees, Alzheimer's Association chapters, faith communities, support groups, etc.),

(3) Able to translate the training manual into a successful training experience for caregivers, and

- (4) Knowledgeable of caregiver training needs and means of recruiting potential caregiver trainees.
- 3. Of the 69 trainers initially trained, 47 trainers proceeded to complete 19 separate workshops to educate at least 208 family caregivers. They invested a total of 392.5 hours (averaging 8.35 hours per trainer) in direct contact with family caregivers. In total trainers contributed 1,341.5 person-contact hours to the project, in addition to the effort required to recruit participants, organize and plan the workshops, and prepare Lesson Plans.
- 4. Project staff were continually available to aid in the recruitment of caregivers for trainers who had difficulty. Outreach social workers, Area Agencies on Aging staff, faith community leaders, and personal contacts were all ideal resources.
- 5. To enable and encourage attendance, the project reimbursed caregivers for adult day care, respite care, and transportation if needed. Trainers were also reimbursed for expenses incurred.
- 6. Caregivers were provided with a series of several workshops (generally, three) lasting between one and four hours each. Some workshops dealt with early issues, some with more problematic symptomology associated with the middle stages of dementia, and some provided information relevant to the late stages of dementia.

# Objective IV: To evaluate the project and disseminate findings for replicability beyond the project period and beyond the geographical regions.

- 1. The project evaluated the effectiveness and utility of the two-day training sessions, demonstrating statistically significantly increases in knowledge among trainers (p < .05). The project staff also documented similar increases in knowledge among caregiver participants and summarized their evaluations of the workshop experiences. In addition, caregivers were surveyed regarding their particular caregiving situations in order to determine for whom the training is most effective.
- 2. Approximately 10% of the caregiver training sessions were monitored by project staff to ensure that the training package protocol was implemented properly.



3. The project has created a master plan for replication which will be disseminated through the Alzheimer's Association network, the Association for Geometria and Human Development in Historically Black Colleges and Universities, Regional Administration on Aging offices, State and local human resource agencies, the Virginia Center on Aging, and the Virginia Geriatric Education Center.

In summary, the project used a train-the-trainer method of disseminating information to two under-served populations -- African American and rural caregivers. The primary products from the project were a training manual, two directories of resources (National and Virginia) on diskette, and this Replication Plan. Each of these products and the Final Report to the Administration of Aging may be obtained by using the order form included at the back of the manual.



#### About the Project Staff

Constance L. Coogle, Ph.D. is the Manager of Information Systems at the Virginia Center on Aging (VCoA) with joint appointments in the Departments of Psychology and Gerontology at Virginia Commonwealth University. She has served the Alzheimer's Association - Greater Richmond Chapter since 1991 as Secretary and Chair of the Medical and Scientific Advisory Committee.

Ruth B. Finley, M.S. is the Assistant Director of Education Services at the VCoA, Assistant Professor of Gerontology, and Core Staff with the Virginia Geriatric Education Center (VGEC). She has served as Board Member and President of the Alzheimer's Association - Greater Richmond Chapter. She has also served on the Governor's Commission on Alzheimer's Disease and Related Disorders from 1989-1994.

Edward F. Ansello, Ph.D. is Director of the VCoA. He has worked on rural issues since 1979, beginning with a project on rural recreation funded by the U.S. Department of the Interior. He co-directed three projects on rural geropharmacy (medications and aging) supported by the Andrus Foundation, and one (1991-1993) supported by the VGEC. His rural publications include a Special Issue on Rural Aging for the journal. Educational Gerontology (1980) and co-editorship of a manual for elder caregivers on medication management (1988). He served as a first level "trainer of trainers" for one of the training programs, discussing special considerations for trainers of rural caregivers.

Michael A. Pyles, Ph.D. is Assistant Director of Health Services Research at the VCoA, Assistant Professor of Gerontology, and Core Staff with the VGEC. He is also a member of the State Health Commissioner's Minority Health Advisory Committee and the VGEC's Statewide Minority Advisory Committee. He served as a first level "trainer of trainers" for the project, developing their ethnic competence and sensitivity to minority caregivers.

Joan B. Wood, Ph.D. is Associate Director of the VGEC and Advisory Council member of the Alzheimer's Association - Greater Richmond Chapter. Her work in the areas of minority and rural aging, as well as family caregiving, has been extensively published. She also served as a first level "trainer of trainers," discussing her academic and personal knowledge of rural aging issues. Her previous AoA-funded projects in Southside Virginia laid the foundation for the current project, and her network of colleagues was instrumental in recruiting many of the advisors, trainers, and caregivers who participated.



#### **About the Centers**

The Virginia Center on Aging (VCoA) was established by the Virginia General Assembly in 1978 as a statewide university-based Center for interdisciplinary study, research, and information sharing. Located in Richmond at Virginia Commonwealth University, the Center's operational focus is applied gerontology, and it provides education, research, training, services, and technical assistance to meet the challenges of achieving healthy and meaningful living in later years. In 1982 the General Assembly established the Alzheimer's and Related Diseases Research Award Fund to stimulate multidisciplinary research in Virginia, and authorized the VCoA to administer the program. Since then, a total of 48 awards have been made in the areas of biomedical, psychosocial, and sociological study.

The Virginia Geriatric Education Center (VGEC) was established in 1985 at Virginia Commonwealth University. Its mission is to promote and enhance geriatric education and curricula in Virginia. The VGEC provides comprehensive educational services and materials to professionals involved in the health care of older adults. The activities are carried out with the cooperation of the Schools of Medicine, Nursing, Dentistry, Pharmacy; the Virginia Center on Aging; the Virginia Institute for Developmental Disabilities; the Office of Continuing Studies and Public Service; University Library Services; the McGuire Department of Veteran Affairs Medical Center; and in cooperation with medical consortium schools at the University of Virginia and Eastern Virginia Medical School.



#### I. INTRODUCTION: THE REPLICATION PLAN IN A NUTSHELL

The Replication Plan for the project, "Assisting Caregivers of Black and Rural Elders with Dementia: Progressive Training Through Trusted Resources," is based upon the Integrated Model for Collaborative Planning and Services to Older Adults with Developmental Disabilities, dubbed the Partners III Project, and directed by Edward F. Ansello, Ph.D. The Integrated Model is a broad, tested process strategy that is relevant for addressing the needs of people who live in the community rather than in institutional settings. The Integrated Model has three basic components which should be incorporated into any replication of this project. These are: 1) collaboration, 2) outreach, and 3) capacity-building. A brief discussion of these three outcomes provides a rationale for replicating the project.

Collaboration. One of the main objectives of the project was to form a partnership of the most relevant and significant organizations that might address the continuing needs of Black and rural caregivers of elders with dementia. These partners served a variety of functions for the project, from guiding the content of the training manual to recruitment of trainers and caregiver participants. Some partners served as first level trainers for the project, providing information about community resources and services available to caregivers, while others conducted caregiver workshops. In the process, agency representatives became better acquainted with others in the caregiving service network and begin to establish or further linkages for future resource sharing, referral, and collaboration.

Outreach. The need for outreach to rural and African American caregivers is well-documented in the manual's Chapters. The attendant barriers to service utilization among these two special populations, important considerations to any outreach effort, were addressed as the project so ght to increase the likelihood that caregivers would access formal supports. Trainers were trained to function as advocates, in a sense, directing and guiding caregivers to those in their communities who could offer assistance. The outreach component of the project was further challenged by the colloquial stigma attached to dementia and Alzheimer's Disease. Yet, the project succeeded in identifying caregivers previously unknown to the local Alzheimer's Association Chapters and providing the foundation for the development of support groups in unserved communities.

Capacity-building. Another major objective of the project was to implement and test the "train-the-trainer" model as a mechanism for caregiver education. In accomplishing this objective the project directly developed the capacities of trusted community leaders who served as trainers of caregivers, indirectly improved the capacities of caregivers through the conduct of workshops, and subsequently increased the ability of elders with dementia to remain, as appropriate, in their communities and avoid premature institutionalization. The train-the-trainer model allowed for the expertise imparted to endure beyond the scope of the project with those in the community who were trained to conduct workshops, and empowered to do so via the training manual materials.



Evaluation. Believing that "anything worth doing is worth doing well," project codirectors added a significant (both in terms of quantity and quality of data) evaluation component to the basic Integrated Model (i.e., the Integrated Model Plus, or IMP). Extensive analysis of the data (i.e., first level training, second level training, caregiver profiles, session evaluations, etc.) enabled staff to assess the project objectively, identify and strengthen the positive elements of the project while minimizing or deleting the less helpful ones. The net result was to produce a more effective plan for replication.

Those who replicate this project through the components of the Integrated Model Plus will not only achieve these stated outcomes, but will also learn much about establishing linkages, networking in African American and rural communities, developing community expertise to strengthen caregiving families, and the importance of evaluating outcomes.



There should be a good fit between your organization and the project to be replicated both in terms of expertise and resources (especially human resources). The organization must have a history of cooperation among colleagues who work with the target populations: rural and African American family caregivers. In the case of rural outreach, ties to trusted and long established networks (grapevines) of "kith and kin" as well as relationships with community agencies/organizations (Alzheimer's Association Chapters, Area Agencies of Aging, Community Mental Health Centers, Adult Day Care Centers, Home Care Agencies, etc.) are essential. In minority outreach, there must be some means of entree into the black religious community, preferably at the State Associational level.

The purpose of this replication plan is to permit interested persons to reproduce the efforts of the project staff. To that end, the extensive Appendix material includes sample forms, correspondence, press releases, flyers, and other items used to promote the activities of the project to facilitate the administrative aspects of conducting such a project.

In order to benefit from the Replication Plan, it is essential to reference the Training Manual, <u>Families Who Care: Assisting African American and Rural Family Caregivers Dealing with Dementia</u>. It is helpful to also reference the Final Report (see Order Form in back).

#### II. THE PROJECT AND THE PEOPLE

#### A. In the Beginning: The Core Staff

The project co-directors, Constance L. Coogle and Ruth B. Finley had first hand knowledge of Alzheimer's and related diseases and the attendent caregiver burden through their



long time service on the Board of Directors and as officers of the Greater Richmond Chapter of the Alzheimer's Association. Coupled with their academic experience (evaluation expertise and adult education respectively), they sought out core staff members knowledgeable about dementia who also had expertise in cultural sensitivity/ethnic competence (Michael A. Pyles), rural issues (Joan B. Wood), and previous experience in a rural train-the-trainer project (Edward F. Ansello). In addition, Dr. Pyles and Dr. Wood also had first hand capabilities in recruitment from the African American and rural communities as well.

#### B. Development of the Ancillary Staff

The capabilities of the core staff was supplemented with several volunteer and ancillary staff. Through an announcement (Attachment 1) sent to the Gerontology graduate students at Virginia Commonwealth University (where the offices of the Virginia Center on Aging and the Virginia Geriatric Education Center are housed), we recruited a terminal Master's student whose specialty track was adult education. She wrote the chapter in the training manual on how adults learn and led an exercise in group work at one of our training sessions. As a result of a guest lecture by the project co-directors in another graduate class at VCU, they recruited an occupational therapist/graduate student to assist them in partial fulfillment of a Certificate in Aging; his project was, in fact, to become a trainer of caregivers, and, as an African American, he was quickly able to recruit appropriate caregivers from his own church as well as conduct the sessions there.

As our "fame" spread (through the VCU newsletter, alumni, etc.) we were able to bring on board an MSW candidate who wrote the module on the grieving process for the training manual and who also assisted in first level training as part of her practicum. She also advised us regarding rural norms and was instrumental in recruiting from rural areas in that she herself had come from a very small community. A MSW with a Certificate in Aging Studies was able to complete a Fellowship with the Virginia Geriatric Education Center by working as a first level trainer, writing the module on safety and environmental adaptations, and assisting with recruitment and the many logistics associated with training.

During the project period, we also had three work study students who did data entry, verified entries for the resource directories, and performed clerical duties. A recent graduate of Old Dominion University with a degree in social work contacted us from South Hill, Virginia. She had read about the project in a newsletter, and was willing to commute to Richmond two days a week as paid staff on the project. Her rural connections were invaluable as was her writing the module on formal supports and resources.

#### C. Making Connections Across the Country

With a well qualified team in place, different members researched resources to enable us to carry out our project without reinventing the wheel. At the national level, more than a dozen linkages were made with appropriate individuals and organizations for the development of our resources library and for consultation. These contacts are shown in Attachment 2. We were



encouraged by the helpfulness of experienced people who were so generous with their time and expertise to develop our project. One of the many helpful letters is shown in Attachment 3.



Don't reinvent the wheel! Get final reports of similar projects from the Administration on Aging (800) 989-6537 or through on line searches (800) 989-2243. Examine the list of consultants used by the current project (Attachment 2) and contact those who "know the ropes."

In addition to human resources, we developed our library of print and audio-visual resources. A sample of the print resources is shown in Attachment 4. Audio-visual Resources reviewed are given in Attachment 5.

#### III. COLLABORATION

#### A. First Steps: Initial Contacts

After developing the core and ancillary staff, networking with other projects and consultants across the country, and establishing a library of print and audio-visual resources, we were able to move onto collaboration with others in the community. Our territory was defined by the cities and counties served by the Greater Richmond and Southside Virginia chapters of the Alzheimer's Association. The leadership in these two chapters in Richmond and in Southside Virginia was essential in carrying out the project. They served as the primary linkages to both families with Alzheimer's and the community resources within their respective territories.

#### B. The Next Step: Building on the Foundation

The next step was to develop a Regional Needs and Resources Team (RNRT) in each of the two territories in which we would be training from a carefully selected cadre of knowledgeable persons who were aware of the needs of families with dementia and also the community resources available to help them. In order to obtain entree to the Black community, project staff wrote, then visited the Executive Director of the Baptist General Convention of Virginia (See Attachment 6). To get a "foothold" in the rural communities, one of the project staff called on contacts in the aging network from her previous Administration on Aging-funded grant. As a "resident" in the community she was already known and respected. Another method of solicitation was sending a letter of introduction (See Attachment 7) to individuals and agencies who would be natural "partners" for the RNRTs. These letters were followed by personal phone calls from staff and an invitation to the first meeting (See Attachment 8).

The project sought individuals with a wide range of expertise and who represented important agencies or organizations (all of the area agencies on aging in the territory, the state unit on aging, minority and majority colleges, agencies representing mental health, housing, social



services, health, primary care, home delivered meals, Veterans Affairs, adult day care, American Association of Retired Persons, Instructional Visiting Nurses Association, black churches, pastoral care, nursing homes, Area Health Education Centers and the Governor's Advisory Board on Aging). In a few cases where the representative had to drop out, someone else from the agency was invited to participate so the input would still be there (see Attachment 9).

Using a nominal group process, the RNRTs brain-stormed content for the training, community resources, barriers to participation, and recruitment strategies. Several people from the group were enlisted to edit modules for cultural sensitivity. In addition to these tasks, the members of the RNRTs were asked to direct us to "access" people, i.e., persons in the community who would know caregivers who could benefit from our proposed training and/or who might be potential trainers of caregivers themselves.

Several members of the RNRTs also served as trainers. The meetings themselves (two meetings for each group) were conducted at either minority institutions (i.e., a Historically Black College or University or church) or rural community colleges. After the first meeting of each RNRT, staff conducted a telephone inquiry to all members of the RNRTs to gauge their impressions of the meeting and to evaluate the composition of the teams (See Attachment 10). Staff surveyed the members of the team with a questionnaire to enable them to best use the expertise of the members and to evaluate the effectiveness of the nominal group process and the comprehensiveness of the content area proposed for the manual (See Attachment 11). The minutes for both groups are shown in Attachment 12 (A-D).

Another important element was that, although the project was grant funded, some of the agencies were able to offer in-kind services and thereby "stretch" the available dollars for more service delivery. For example, all the facilities for meetings (community colleges, HBCUs, churches, etc.) were provided rent free. In some cases, the host even provided the refreshments or catered the meal at cost. Likewise audio-visual equipment was made available at no charge to the grant.



The RNRTs were the catalysts which linked our project with the needs and the families of persons with AD and also identified the available resources in their communities. The project could not have been successful without this essential ingredient.

#### IV. OUTREACH

#### A. Marketing to Potential Trainers

The project itself was marketed widely within the territory in which we were planning to conduct training. Press releases were sent to the newspapers and all the members of our RNRT



(who had their own distribution networks). Information was published in the quarterly newsletter of the Virginia Center on Aging and the Virginia Geriatric Education Center, "AGE in Action," and similar routes included the newsletters of each of the two Alzheimer's chapters involved and in-house organs. Several attachments, 13 (A-C), indicate how to write a press release and how different agencies used them.

More specific targets were obtained by working through the Virginia Baptist General Board, the Virginia Council of Churches, and 135 ministers of rural churches (the latter being obtained by two rural ministers, one being the President of the Southside Chapter of the Alzheimer's Association!) (See Attachment 14 (A-C). A sample of how this kind of marketing was spread through the rural church network is shown in Attachment 15. A similar letter was sent to some 250 community leaders who had been identified from various sources to announce the project and call for caregiver trainees from the two targeted groups (See Attachment 16). Staff made personal appearances at the meeting of a rural black Baptist Association, the Central Virginia Chapter of the Black Nurses Association, and local churches. We also marketed to the Alliance for Black Social Welfare, Inc. (See Attachment 17).

Although the press releases were somewhat effective, the best recruitment technique to enlist potential trainers for training was the very labor intensive method of a personal phone call (usually about 30 minutes) or a meeting (about an hour). A list of the names of 141 potential trainers (almost four times as many as we thought we would need) had been developed from the press releases, personal phone calls, and visits. In addition, a second list of "access resources" had been identified through leads from the RNRTs and personal contact, and those persons were invited to participate in one or more ways, as follows: (1) become a trainer; (2) lead us to other potential trainers; and (3) most importantly, assist trainers in identifying caregivers by marketing our proposed training to their constituents at a later time.



Recruitment of trainers and other volunteers is more successful through face-to-face meetings, personal phone calls, and group presentations rather than mass marketing. Posters, press releases, print and electronic media should be employed, but your more labor intensive and time consuming efforts to meet with individuals will probably yield more and better results.

The project recruited trainers of caregivers who were: 1) knowledgeable of caregiver issues, especially caregiving for dementia victims; 2) in touch with caregiver networks locally (Area Agencies on Aging, Social Services, local Long Term Care Coordinating Committees, Alzheimer's Association chapters, faith communities, support groups, etc.); 3) able to translate the training manual into a successful training experience for caregivers; and 4) knowledgeable of caregiver training needs and means of recruiting potential caregiver trainees. Staff was also very selective in its trainers: in addition to being trusted in the community, and having particular expertise, those who knew caregivers and could encourage their participation were especially



sought. For all these reasons, the recruitment of potential trainers was laborious but well worth the effort. (The actual training of trainers will be described in the session on capacity-building).

Once a sizeable pool of potential trainers had been developed, staff was equipped to hold orientation meetings throughout the territory for all potential trainers who had been identified. The largest meeting was held at a minority institution (the Baptist General Convention of Virginia in Richmond). At this meeting project staff presented an overview of the entire project, provided a list of all potential trainers and access resources, and shared a first draft of the table of contents for the training manual along with the first draft of a sample module in the manual (graded for literacy appropriateness). In addition we provided a copy-ready flier for use in recruitment of fellow trainers (See Attachment 18) and helpful handouts, e.g., "Suggestions for a Successful Outreach Program in African American Communities" (Attachment 19). "Suggestions for a Successful Outreach Program in Rural Communities" (Attachment 20), "How to Recruit Caregiver Trainees" (Attachment 21), and "Tips for Setting up a Successful Workshop" (Attachment 22). These materials were also sent to RNRT members, Access Resource (or Caregiver Contact) persons, and potential trainers who could not attend orientation meetings. As new potential trainers were identified, they were also sent these materials, along with a letter of welcome (See Attachment 23).

The recruitment of 141 potential trainers had taken months; hence, some who had been the first contacts were "raring to go." In order to keep them engaged, we periodically sent all the potential trainers recruited to date a mailing of pertinent articles, bibliographies and other information to maintain their interest and to allow them to begin educating themselves about dementia and caregiving.



Trainers must demonstrate commitment to the project, compassion for the caregivers and fidelity to the content. No matter how well prepared trainers are, they have to be ready for the unexpected because education is dynamic experience and requires flexibility to adjust to the needs of the caregivers.

In essence, there were several incentives to become a trainer. They would receive two full days of training, a substantive training manual, materials from local community resources, a Resource Directory for their locale (either Southside Virginia or Central Virginia), and Continuing Education Units (CEUs) from the Virginia Geriatric Education Center at Virginia Commonwealth University. In return, they simply had to commit to conducting one group of African American and /or rural caregivers in which they would cover the nine required modules (and hopefully some of the other ones) and document it as prescribed. In addition, Chapter 5 of the Training Manual spelled out all the steps of recruitment, preparation, conducting the session, evaluating, etc. Trainers were free to format the sessions (e.g., the number and duration of sessions) to meet the needs of their caregivers and themselves. In short, it was a good deal for trainers!



#### B. Marketing to Potential African American and/or Rural Caregivers

Trainers were theoretically responsible for recruiting their own trainees, and indeed, we uncovered evidence of their efforts early on in the project (See Attachment 24). Although they were encouraged to start that process immediately, some felt reluctant to do so because they had not yet been trained by us and hence were not able to give potential trainees the exact dates of that caregiver training (Level 2) would occur. (The recruitment of Level 1 trainers was well ahead of schedule but the writing/publishing of the training manual was slightly behind schedule, so there was about a three-week "lag" in our first set of Level 1 training dates). During Level 1 training, staff presented them with extensive recruiting techniques during their two-day training and they were more comfortable in the role of recruiters. Even so staff facilitated the process by sending press releases which were picked up by state associations such as the Virginia Health Care Association, Virginia Association of Homes for Adults, and the Virginia Association for Home Care, etc., as "insurance" (See Attachment 25). In addition to media outreach, staff began a letter writing campaign to: 1) network with clergy previously identified (see Attachment 26), and 2) families in metro Richmond via the Alzheimer's registry in the State Department of Health (see Attachment 27).

The most difficult part of the project was the recruitment of caregivers. Many caregivers were so tied down already that going to a training session was viewed as yet another thing to do. In rural areas with the population spread out over vast distances, transportation was often a problem. In some situations, there was no one to take care of the family member for them to attend training. Some caregivers still felt a stigma associated with dementia and were embarrassed. Others felt like they could "take care of their own." In all press releases it was stated that limited aid was available to assist with mileage reimbursement and respite care. Due to reasons of confidentiality, staff kept itself at arm's length and did not ask for the names of any caregivers unless they volunteered their names and asked to be called by us or if they called us themselves.

#### V. CAPACITY BUILDING



Even though the aging network is serving an unprecedented number of older adults, many persons with dementia are "unknown" to the system, and often times family caregivers are struggling alone without knowledge or information about services that could help them. By identifying and partnering with family caregivers, not only can the aging network (both academicians and practitioners) leverage their limited resources dramatically, but family members can "ease the burden" through knowledge of services.



#### Level 1: Building the Capacities of Trainers

#### A. <u>Preparation for Training of Trainers (Level 1)</u>

In order to plan the first training sessions, staff mailed potential trainers a letter with a Return Feedback Form (Attachment 28) to determine the number of times and places staff would repeat the full two day training. After polling potential trainers, staff was able to establish dates for four sets of two-day training events at several different sites within the territory. The number of sites was determined by the size of our territory and the "pockets" of trusted community resources. Each of the two-day events was back-to-back, as that was the most cost-, time- and travel-effective scenario. We sent a memo to all potential trainers detailing the dates, sites (which included a HBCU, a community college, and a nursing home), directions, registration form/questionnaire (including the number of caregivers they had recruited), and a return address label [See Attachment 29 (A-C)]. One of the best training sites was a HBCU (see Attachment 30 for letter of request). For those who did not return their registration/questionnaires, we followed up with a phone call. We offered additional incentives (e.g., mileage reimbursement in rural areas, although few requested it since they're used to driving substantial distances to get anywhere).

The training manuals were prepared in a three-ring binder with pockets on the inside covers. Other hand-out materials were collected (brochures, booklets, and materials on minority health issues, Alzheimer's Disease and related disorders, geriatric alcoholism, etc.). The Virginia Geriatric Education Center offered Continuing Education Units (CEUs) free of charge. Most importantly a panel of local resources (e.g., local chapter of the Alzheimer's Association, adult day care, area agencies on aging, local departments of social services, community mental health centers, etc.) was assembled to complement the presentations of the core staff. Prior to the training event, each of the panelists was given a case study typifying a dementia caregiving family to which they could respond as to how their agency or organization could assist the family. This activity proved to be especially helpful for trainers who would find themselves acting as advocates for caregivers, facilitating their entry into the service system and/or arranging for respite care if needed for caregivers to attend training.



Family caregivers need to become better aware of existing resources and services within the community to enable the person with dementia to remain in a community setting. However, family members are often poorly informed regarding such resources. One of the most useful methods of ultimately linking families with needed services was to equip trainers with a comprehensive knowledge of community resources via the Resources Panel (AAAs, CSBs, Social Services, etc.). Trainers could then get literature and further information to share with their caregiver trainees. By implementing the Integrated Model Plus (IMP), the capacities of trusted community leaders and informal caregivers can be developed.



#### B. Training of Trainers (Level 1)

The agenda for all four two-day training sessions was essentially the same except for modifications for improvement that were made in response to feedback from the trainers. For example, after the first session, training packets included a Certificate of Appreciation to be awarded to caregivers at the completion of their workshops (see Final Report).

The agendas for each training day [see Attachment 31 (A-B)] remained consistent in that components could not be "swapped" from one day to the other; nor did it matter whether Day B came before Day A. This protocol was followed to accommodate those trainers who could not take Day A and Day B back-to-back, but might in fact take Day B at one site and Day A at another due to scheduling conflicts.

One significant part of training was role-playing a "typical" session in order to point up possible issues that might come up (e.g., literacy level, cultural and age-cohort norms, age-related sensory losses, etc.) The role play illustrated the need for good prior planning (e.g., site visit, equipment, hand-outs, refreshments, room set-up, security, accessibility, etc.).

The team building aspect of training was significant. We encouraged trainers to go out "two by two" in order to complement their skills. For example, one person might be a greater asset as a "trusted community resource" if he/she were older, minority, better known, etc., whereas the partner might be an educator by profession or have personal caregiver knowledge or expertise in the content areas. Additionally they could encourage each other and share the responsibilities, e.g., one could get the hand-outs copied and the other could arrange for the video. In some cases, the team of "two" expanded to several members. From the monitoring that staff later did of selected sessions, these larger teams were robust in their preparations and presentations and could in fact provide more "perks" (e.g., a potluck dinner instead of light refreshments) because they could share the responsibilities. The number of caregivers they trained, however, was not correspondingly larger than that of the smaller teams.

One of the two-day events was videotaped and subsequently edited for the benefit of a few trainers who were identified after the Level 1 training had been completed. For those people, staff provided a one-day abbreviated session to complement the tape and to provide some face-to-face interaction between trainers and staff.

The abbreviated training day was also planned to accommodate training participants who could not attend the sessions scheduled. It was reasoned that those already knowledgeable about caregiving, dementia, and the aging network could proficiently conduct the workshops without the benefit of additional training in those areas. Alternatively, those who needed the more indepth training could gain it through viewing the videotape made of the training event and careful study of the training manual. Ideally, abbreviated training participants were those who had some background in aging, Alzheimer's Disease, or caregiving since the overview of dementia and caregiving issues were necessarily omitted from the abbreviated agenda. Those who felt the need for extended training in these areas, in addition to the information provided in the training



manual, were sent supplementary videos subsequent to the training. The panel of representatives from community services agencies was also omitted from the abbreviated training session. It was anticipated that the caregiver resource directories prepared for two-day training participants would suffice. Trainers were also urged to carefully study the Caregiver Lesson Plan on Using Formal Supports and Resources and investigate the services available prior to the conduct of caregiver workshops. In addition, materials (brochures, flyers, etc.) provided by members of community resource panels were distributed to abbreviated training participants.

Training content included:

- 1) a review of the project's purpose and rationale;
- 2) developing ethnic competence for cross-cultural training;
- 3) special considerations for trainers of rural caregivers;
- 4) sensitivity training on building trust and dealing with instances of unintentional abuse or benign neglect;
- 5) a demonstration of adult learning principles; and
- 6) specific instruction on how to identify and recruit caregivers, find a training site, conduct the workshops, and collect evaluation information.

The abbreviated training session concluded with a demonstration of how an actual workshop might be conducted.

In summary, we issued a personal challenge to trainers, in which we made it clear that they were capable of recruitment and training and how they should prepare themselves for the task. "If you care, you can. If you sincerely believe you can improve the quality of life for caregivers and for those for whom they care, you can overcome stereotypes and prejudices you may have grown up with. You have the ability to facilitate an increase in knowledge, a change in attitudes/behaviors, and the development of skills through training."

An extensive and highly technical analysis of Level 1 Training is an appendix of the Final Report (See Order Form in back). The key points from Level 1 training are summarized in the evaluation section of this plan.

#### Level 2: Building the Capacities of Caregivers

As indicated before, it was the responsibility of the trainers to recruit and train "their" people, and we did send a "strongly" worked letter (See Attachment 32) to those who had not initiated any action. A "less strongly" word letter was sent to potential trainers who were likely to follow through with their commitment, but had yet to do so (See Attachment 33). In all cases, staff was as supportive as possible. For example, staff customized (i.e., a rural and minority version) bulletin inserts for churches to insert into their bulletins to advertise the forthcoming training opportunity. (We printed more than 6,000 of them!) Attachment 34 (A-B) shows two versions of the church bulletin insert---the factual one we started with a the more user-friendly one we changed to. We deleted "Medical College of Virginia" from our address because a



member of our Southside RNRT said that when people go to MCV they're sick enough to die! Someone else indicated that the reference immediately made people wonder, "Who are these people from the Medical College and what do they want from us?"

We worked almost daily in connecting trainers with access resources in their area. In addition, we kept a calendar of when and where trainers had scheduled training sessions, so we could refer names to them. Through a data base established by prior research, staff was able to identify a sizable number of African American caregivers. After mailing a notice about the workshops to them, a number of them called us and we were able to refer them to the training sessions closest to them.

The Alzheimer's chapters were highly supportive and permitted trainers to make a personal appearance and answer questions concerning their upcoming training sessions. Similarly there was financial aid to encourage the participation of caregivers who could not attend training without paid respite care. In one interaction among the project staff, the Alzheimer's Association chapter, the area agency on aging, and the trainer, we were able to provide respite not only for the course of the training but get the caregiver into the "system" so that she could get additional (and much needed) respite later on.

Chapter 5 in the training manual ("Recruitment of Caregivers and Conducting Workshops") provides sections on: identifying and recruiting caregiver trainees; contacting caregivers and asking them to become trainees; obtaining a commitment to attend the workshops; finding a site to hold the workshops; preparing for the workshops; how to use the caregiver lesson plans (modules); building trust; discovering unintentional abuse and neglect; evaluation; and conclusion. There are seven addendum items to complement the chapter.

Staff prepared and distributed two Caregiver Directory of Resources unique to each of the two territories (see Final Report), to supplement the many copy-ready unpaginated hand-outs that were included in the training manual. Furthermore, because of their two-day training, trainers could obtain brochures from each of the panelists they had met during their training. Two Suggested Reading Lists for Caregivers were also sent to trainers for use during their workshops [see Attachments 35 (A-B)].

Our initial thought was that if 60 trainers divided into teams of two (30 teams) and if each team recruited 10 persons, then 300 caregivers would be trained. This is not what happened. Teams ranged from one person to a "coalition" of several, and the size of the groups ranged from one to 30!





The "take home" message from our experience was to be conservative in the number of individuals you plan to reach and concentrate on strengthening the commitment of each trainer to carry out his or her commitment. Another lesson learned was that by targeting our outreach to only African American and rural caregivers, we limited the numbers we could reach; however no one was turned away if he/she did not meet the criteria.

There were some expenses associated with the project (e.g., printing, postage, etc.), all of which were higher than anticipated. In replicating the plan, it would be wise to seek in-kind donations of space (perhaps even someone's home if they have a VCR), free use of videos from the local Alzheimer's chapter or area agency on aging, etc., free copying 1. om the trainer's own agency, if applicable, etc.

#### VI. RECORD KEEPING AND EVALUATION

Record keeping and evaluation are significant components of the IMP. With respect to the Regional Needs and Resource Teams, <u>formative evaluation</u> regarding the utility of the nominal group process of consensus building for determining African American and rural caregivers' educational needs, and the composition of the RNRTs, is essential. Since all project activities (e.g., recruitment of trainers and caregivers, first and second level training) stem from successful collaboration, formative evaluation provides an effective method of establishing relevant training curricula and assuring that all appropriate partners are involved.

Summative evaluation of the first level training (i.e., the training of trainers) provides project staff with an indication of how well the training content was understood. The results of pre-training and post-training knowledge tests may be used to determine where further training or additional information is needed. The results of participants' evaluation of one training session (i.e., applicability and utility of content, effectiveness of presenters, etc.) can be used to improve subsequent sessions. The knowledge questionnaires used to measure knowledge gains among trainers in the current project have been revised on the basis of item analyses. The revised questionnaires are included in Appendix II along with the Training Session Evaluation Form.

Summative evaluation of the second level of training (i.e., training of caregivers) provides tangible proof that workshops have been successful, that caregivers have learned the workshop content, and that they have benefitted from their participation. By reviewing the results of evaluation questionnaires trainers of caregivers can easily revise the structure of workshops (e.g., include more video material, spend additional time on certain content areas, or adjust their presentational style). The knowledge questionnaires used to measure knowledge gains among caregivers in the current project have been revised on the basis of item analyses. The revised questionnaires are included in Appendix II along with the Workshop Evaluation Form.



Note: As an alternative to pre-workshop and post-workshop testing, trainers may choose to use the knowledge questionnaire as a didactic aid to reinforce key points by administering the test only at the end of the lecture, and then reviewing the correct answers before the group.



Reduce the amount of paperwork that caregivers must fill out, and simplify that which is really necessary. From their point of view, it is artificial and detracts from the learning experience. Furthermore, it makes more work for the trainers.

Because the collection of evaluation data was such a priority for the current project, a great deal of time was devoted to teaching trainers how to administer questionnaires. Chapter 5 of the Training Manual, "Recruitment of Caregivers and Conducting Workshops," provided trainers with detailed instruction. The importance of returning questionnaires after <u>EACH</u> workshop was emphasized (see Attachment 36), and workshop coversheets (see Appendix II) to be completed and returned with each set of evaluation data were provided. Trainers were made aware of the need for careful and meticulous data collection. For example, the imperative of having matching pre-workshop and post-workshop questionnaires was underscored. Those who replicate this project must remember that the comprehensiveness and veridicality of any evaluation effort is limited, first and foremost, by those who collect the data.

Generally speaking the evaluations revealed that the participants were generally satisfied with the training and felt the experience was beneficial. They were impressed with the scope and comprehensiveness of the training manual. They were qualified, enthusiastic, appreciative and committed to the goals of the project. Several announced their intention to continue with small training groups after the duration of the project. Others expressed how they planned to adapt the training materials for use with other audiences and for purposes that exceeded those of the grant.

Because project staff arranged for an abbreviated training day, evaluation responses provided by those participants were compared with those attending the full (two-day) training. If comparable evaluation results were obtained, it was reasoned that perhaps the less intensive and time consuming training would suffice. A detailed report of this comparison is given in the Final Report. Essentially, the results of abbreviated training were the same as the more extensive training in that the training was well received with high marks in all areas of evaluation. A statistically significant overall gain in knowledge was demonstrated. A direct comparison was statistically inconclusive, however, due to differences in samples and the possibility of a ceiling effect and a "halo" effect operating in the abbreviated training respondents. Lacking confirming results, the project evaluator recommends that the more extended format be used.

An extensive and highly technical evaluation of Level 2 training is included as an Appendix item in the Final Report (see Order Form in back). Generally speaking, the caregivers were gratified and indicated that sessions exceeded their expectations in their



evaluations. That's not surprising, based on the sessions which staff monitored (see Attachment 37).

#### VII. SUMMARY

To replicate the train-the-trainer model employed by this project, follow the sequential steps listed below, although various tasks will be going on simultaneously (e.g., recruitment of trainers, development of curriculum, development of local, state, and national resource directories, etc.).

Identify members to serve on RNRTs

Convene meetings of RNRTs

Start networking with lists of RNRT members, Access Resources, and potential trainers

Order audio-visual and other resources

Recruit trainers

Set dates, sites and format of training

Prepare trainers with reading lists, resource directories, etc.

Finalize all materials to be used in training and print

Conduct multiple sets of training as needed

Monitor Caregiver Workshops conducted by trainers

Follow through on all trainers to keep them on task and provide technical assistance

Collect caregiver evaluation data from trainers

Publish results and disseminate products (resource directories on disk, etc.)



Be realistic about your time frame. Double the amount of time that you think each step will take!!



## APPENDIX I

Replication Plan Attachments



### List of Appendix I - Attachments to Replication Plan

| 1)       | Press Release to Gerontology Graduate Students                          |
|----------|---|
| 2)       | List of Individuals/Organizations Contacted Nationally                  |
| 3)       | Sample Letter of Cooperation and Resource Sharing                       |
| 4)       | Partial List of Printed Resource Material Reviewed                      |
| 5)       | Audio-visual Resources Reviewed   |
| 6)       | Letter to Executive Director - Baptist General Convention of Virginia   |
| 7)       | Letter of Introduction  |
| 8)       | Invitation to 1st RNRT meeting  |
| 9)       | Letter Asking for RNRT Member Replacement                               |
| 10)      | Results of Telephone Inquiries to RNRT Members                          |
| 11)      | Regional Needs and Resources Team Questionnaire                         |
| 12, A-D) | Minutes from 1st and 2nd RNRT meetings in Central and Southside Virgini |
| 13, A-C) | Sample Press Release and Utilization by Agencies                        |
| 14, A-C) | Sample of Letter to Members of the Clergy                               |
| 15)      | Example of Reference to Workshops in Church Bulletin                    |
| 16)      | Caregiver Recruitment Letter to Community Leaders                       |
| 17       | Sample Marketing Letter to Black Professional Organization              |
| 18)      | Copy Ready Flyer to Recruit Caregivers                                  |
| 19)      | Suggestions for Outreach In African American Communities                |
| 20)      | Suggestions for Outreach In Rural Communities                           |
| 21)      | Handout on How to Recruit Caregiver Trainees                            |
| 22)      | Tips for A Successful Workshop  |
| 23)      | Letter of Welcome to New Potential Trainers                             |
| 24)      | Recruitment Flyer Developed By Trainers                                 |
| 25)      | Sample Use of Press Release to State Associations                       |
| 26)      | Appeal to Clergy Requesting Identification of Caregiver Trainees        |
| 27)      | Memo to Families sent Via Alzheimer's Registry                          |
| 28)      | Return Feedback Form for Trainers                                       |
| 29, A-C) | Memo Requesting Workshop Dates/Times & Scheduling Feedback Form         |
| 30)      | Letter of Request to Host Training Days                                 |
| 31, A-B) | Agendas for each Training Day   |
| 32)      | Strongly Worded Letter Urging Trainers to Schedule Workshops            |
| 33)      | Gently Worded Letter Urging Trainers to Schedule Workshops              |
| 34, A-B) | Two Versions of Church Bulletin Insert                                  |
| 35, A-B) | Two Suggested Reading Lists for Caregivers                              |
| 36)      | Memo Emphasizing the Importance of Proper Data Collection Procedures    |
| 37)      | Form Used to Monitor Caregiver Workshops                                |
|          |   |



#### PART-TIME EMPLOYMENT OPPORTUNITY FOR STUDENT

Student Needed to Work Half-time (20 hours each week) for the Summer 1994

The Virginia Center on Aging project to assist caregivers of elders with dementia in rural and/or African-American families is currently seeking a student with word-processing skills (Word Perfect 5.1) to finalize project products (training manual, community resources directory, & replication plan).

- \* Complete familiarity with Word Perfect 5.1 is essential
- \* Good organizational skills and attention to detail a plus

Other job responsibilities will include miscellaneous office assistance and activities related to product dissemination.

If you or someone you know has the requisite abilities please contact:

Ruth Finley or Constance Coogle at 804/786-1525 and/or send resume to:

Virginia Center on Aging P.O. Box 980229 Richmond, VA 23298-0229



# List of Individuals/Organizations Contacted Nationally for Purposes of Resource Sharing/Consultation

Edna Ballard, Duke University Alzheimer's Disease Research Center

Share DeCroix Bane, National Resource Center for Rural Elderly

Gail Cheatham, Alzheimer's Association - Southeastern Wisconsin Chapter

Helen Duran, National Resource Center on Rural Aging

Diane Freeman, Administration on Aging

Leo Givs, Alzheimer's Association - Washington, D. C. Chapter (satellite office)

Kara Kennedy, National Alzheimer's Association, Multicultural Outreach Coordinator

Helen Knierim & Carolyn Rizza, Slippery Rock University, Rural Elderly Assessment Project

Debbie Leech, National Eldercare Dissemination Center

Leigh Meyers, Alzheimer's Association - Detroit Area Chapter

Andrea Nevins, National Eldercare Institute on Human Resources

Jean Schensul, Institute for Community Research

Virginia Schiaffino, National Federation of Interfaith Volunteer Caregivers, Inc.

Carol Simpson, Alzheimer's Association - Washington, D.C. Chapter

Ernestine Williams, Minority Outreach Coordinator, Alzheimer's Association - Great Philadelphia Chapter (satellite office)

Mary Williams, Director of Caregivers Information and Training Program, Morehouse School of Medicine





SOUTHEASTERN WISCONSIN CHAPTER 1300 South Layton Blvd • Milwaukee. WI 53215 414-645-8887 • Fax. 1-414-645-5090

July 19, 1993

Ruth B. Finley, M.S. Project Co-Director Medical College of Virginia Virginia Commonwealth University Virginia Center on Aging Box 229 Richmond, VA 23298-0229

Dear Ms. Finley:

Our current Multi-Cultural brochure resulted from a long but successful process of:

- . Securing special permission to use photos of residents attending an adult day care facility in Milwaukee
- . Collaborative meetings to determine:
  - . the informational needs of the target audience
  - . culturally relevant language to supply needed information
  - . appropriate lay-out to encourage reading the brochure

This method was instrumental in the development of a brochure that could be used as a resource guide to access services for African Americans affected by Alzheimer's disease.

Your Train-the-Trainer hand-outs were clear and culturally sensitive. To encourage the success of your program, I have enclosed an introduction to a resourceful book that you might find helpful in the provision of services for your constituency.

If I can be of further assistance on your excellent project, please feel free to call  $m_{\rm H}$  at (414) 645-8887.

Sincerely,

Gail Cheatham

Multi-Cultural Outreach Coordinator

GC:se

Enclosure

**BEST COPY AVAILABLE** 



#### Partial List of Printed Resource Material Reviewed

Educational Materials and Innovative Dissemination Strategies: Alzheimer's Disease among Puerto Rican Elderly; Final Report by Jean J. Schensul, Ph.D.; Institute for Community Research; Hartford, Connecticut

Family Caregivers & Caregiver Training; A Filmography from the National Eldercare Institute on Human Resources; Brookdale Center on Aging of Hunter College; American Society on Aging

Alzheimer's Dementia & Behavioral Disorders; A Filmography from the National Eldercare Institute on Human Resources; Brookdale Center on Aging of Hunter College; American Society on Aging

How to Cope with Alzheimer's Disease: Training Manual by Jill R. Boyd et al.; Alzheimer's Association - St. Louis Chapter

Care to the Caregiver in Alzheimer's Disease: A Curriculum Guide by Marcela Gutierrez-Mayka, Ph.D.; The National Resource Center on Alzheimer's Disease; Suncoast Gerontology Center; University of South Florida

Minority Alzheimer's Caregivers: Removing Barriers to Community Services; A Training Manual by J. Neil Henderson, Ph. D. et al; The National Resource Center on Alzheimer's Disease; Suncoast Gerontology Center; University of South Florida

Blacks and Alzheimer's Disease: A Caregivers Information Project by Dr. Mary P. Williams; Morehouse School of Medicine; Atlanta Georgia

Practical Help Caring for an Elderly Person in the Community: Instruction Guide for Course Leader; New Your State Office for the Aging

Caregivers Practical Help: A Six Session Course for Informal Caregivers; New Your State Office for the Aging

Caring for Alzheimer's Patients: Supplement to Caregiver's Practical Help; New Your State Office for the Aging

Managing the Person With Intellectual Loss (Dementia or Alzheimer's Disease) at Home; The Burke Rehabilitation Center Auxiliary; White Plains, NY

Caregiving: Making the Transition - A Self-care Program for Caregivers and Families of Alzheimer's Victims by C. Wyman; Andrus Gerontology Center, USC

The Caring Home Booklet: Environmental Coping Strategies for Alzheimer's Caregivers by J. Pynoos et al.; Andrus Gerontology Center, USC



Caring: A Family Guide to Managing the Alzheimer's Patient at Home by F. Tanner; Alzheimer's Association - New York City Chapter

Rural Elderly Assessment Project: Preliminary Findings by Carolyn C. Rizza; Slippery Rock University; Slippery Rock, PA

Rural Elderly Assessment Project: Manual by Helen Knierim, Ph.D. & David Fox, M.A.; Slippery Rock University; Slippery Rock, PA

Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses; Geriatric Education Center of Michigan

Optimum Care of the Nursing Home Resident with Alzheimer's Disease by Edna Ballard and Lisa Gwyther; Duke University Medical Center



#### Materials To Be Reviewed

- "Alzheimer's Disease: Pieces of the Puzzle," A Training Program for Direct Service Staff and Family Caregivers Instructor's Manual and five-part video series. Developed by The Arizona Long Term Care Gerontology Center at the Arizona Health Sciences Center, The Unviersity of Arizona.
- "Alzheimer's Disease and Ministry," An Overview with the Professionals (A Training Program for the Clergy). University of Pittsburg, Alzheimer's Disease Center (Cassette Tape). Including "Even These May Forget (A Pastoral Care Challenge: Training Program for Clergy) (Videocassette).
- "Alzheimer's 101: The Basics for Caregiving," Produced by South Carolina ETV in Cooperation with the South Carolina Commission on Aging (Videocassette). Including Learner's Guide and Trainer's Manual.
- "Managing and Understanding Behavior Problems in Alzheimer's Disease and Related Disorders," Ten-Part Videocassette Series. University of Washington, Alzheimer's Disease Center.
- "Alzheimer's Caregiver Problem Solving Method: Improving Caregiver Skills" (Part I).

  University of Southern California, ALzheimer's Disease Center. Including "Alzheimer's Caregiver Stress Reduction Method: Improving Caregiver Skills" (Part II).
- "Caring for the Cognitively Impaired Patient," Five-Part Videocassette Series. Including User's Guide, Teacher's Guide, and Appendices. University of Kentucky, Alzheimer's Disease Center.
- "Nurse's Aides: Making a Difference: Skills for Managing Difficult Behaviors in Dementia Victims." Including A Viewing Guide. University of Texas Southwestern Medical Center, Alzheimer's Disease Center.
- "The Mental State Examination in Dementia," (Two-Parts). Including a Study Guide. The John Hopkins University, Alzheimer's Disease Center.
- "Detecting Dementia: Cognitive Assessment for Home Health Care Professionals." Including Instructor's Guide. Washington University, Alzheimer's Disease Center.
- "Speaking for Them: Identifying Psychiatric Complications in Alzheimer's Patients." Including Manual. University of California, San Diego, Alzheimer's Disease Center.
- "Geriatric Assessment: A Functionally Oriented, Ethnically Sensitive Approach to the Older Patient." Including Study Guide. Stanford Geriatric Education Center.



November 28, 1994

Rev. Cessar L. Scott Baptist General Convention of Virginia 1214 Graham Rd. Richmond, VA 23220

Dear Rev. Scott:

I spoke with you on the phone today about the possibility of working with your organization as we accomplish the goals of our project entitled "Assisting Caregivers of Minority and Rural Elders with Dementia." As you may recall, I indicated that the Virginia Center on Aging has obtained funding from the federal Administration on Aging to improve eldercare services for rural and minority dementia patients in Central and Southside Virginia. The overall goal of the project, is to develop and deliver effective methods to identify and train these caregivers.

The project will convene regional planning groups that represent organizations that are the most relevant and significant to rural and minority caregivers, e.g., state and local government, majority and minority institutions of higher education, local chapters of the Alzheimer's Association, churches, and various service provider organizations. These groups will help identify and respond to the continuing needs of these caregivers of elders with dementia. The process will enable the project to develop both training materials for caregivers and linkages among personnel involved in service delivery to elders with dementia and their families.

These planning groups, called Regional Needs and Resources Teams, will advise the project staff and assist in recruiting trainers who are knowledgeable of caregiver issues and training needs, connected with caregiver networks locally, and capable of recruiting potential caregiver trainees. In addition, the Teams will guide the development of the training curriculum, ensuring the use of appropriate and culturally sensitive materials. A special feature is that the project will develop training materials organized according to the likely progression of the dementia, so that caregivers will have information that relates to the needs of the person cared for.

We would appreciate any assistance you can provide in our efforts to work with African American churches in our territory as we form our Regional Needs and Resources Teams. The success of our project will depend in part on the goodwill and cooperation of trusted community leaders, especially those who are active in the church. Our goal is to reach out to caregivers who have been reluctant to utilize formal services. Since many of these individuals have turned to the church for help, religious leaders are in a unique position to help us identify those who could benefit from the services we will offer.



Enclosed please find the news release announcing our grant award and the project summary that was included with the grant proposal to the federal Administration on Aging. I have also included other pieces of the grant proposal for further clarification of our project.

Thank you for your interest in our project. I look forward to speaking with you the first week in December.

Sincerely,

Constance L. Coogle, Ph.D. Manager of Information Systems

Enclosures

cc: Ruth B. Finley, Co-Investigator



November 28, 1994

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#### Dear 6~:

The Virginia Center on Aging has obtained funding from the U. S. Administration on Aging to improve eldercare services for rural and minority dementia patients in Central and Southside Virginia. Dementia is as prevalent, if not more so, among minority elders, and minority and rural families are often unconnected to resources that might help in caring for their elders with dementia.

The overall goal of the project, entitled "Assisting Caregivers of Minority and Rural Elders with Dementia," is to develop effective methods to identify and train these caregivers. The project will convene regional planning groups that represent organizations that are the most relevant and significant to rural and minority caregivers, e.g., state and local government, majority and minority institutions of higher education, local chapters of the Alzheimer's Association, churches, and various service provider organizations. These groups will help identify and respond to the continuing needs of these caregivers of elders with dementia. The process will enable the project to develop both training materials for caregivers and linkages among personnel involved in service delivery to elders with dementia and their families.

These planning groups, called Regional Needs and Resources Teams, will advise the project staff and assist in recruiting trainers who are knowledgeable of caregiver issues and training needs, connected with caregiver networks locally, and capable of recruiting potential caregiver trainees. In addition, the Teams will guide the development of the training curriculum, ensuring the use of appropriate and culturally sensitive materials. A special feature is that the project will develop training materials organized according to the likely progression of the dementia, so that caregivers will have information that relates to the needs of the person cared for.

The success of our project will depend in part on the goodwill and cooperation of trusted members of the community, especially those who have direct contact with these families, since they are in a unique position to help us identify those who could benefit from the services we will offer.

We have attached a news release announcing the project and hope that this letter will serve to inform you of the initiative and of our plans for the formation of the Regional Needs and Resources Teams. If you could contribute to the work of our Regional Needs and Resources Teams, please contact us as soon as possible. Please share this information with



others who, in your estimation, would significantly contribute to the work of this group. Clearly, the success of our project depends upon the careful selection of the most appropriate representatives to actively participate on the Regional Teams.

Thank you in advance for your assistance. Everyone on the project looks forward to working with you, and others you identify, on this important project.

Sincerely,

Ruth B. Finley
Project Co-Director

Constance L. Coogle, Ph.D. Project Co-Director

Enclosure



December 9, 1992

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Dear 6~,

Our first meeting with potential members of the Regional Resource Team is scheduled for Wednesday, December 16, 1992 at 2:00 p.m. at the Alzheimer's Association - Greater Richmond chapter, 6767 Forest Hills Avenue, second floor conference room (see enclosed map). Our agenda is to overview the key points of the Administration on Aging project which is a train-the-trainer model in which rural and/or minority family caregivers will be the ultimate beneficiaries. We are looking for the combined expertise of a variety of educators and service providers to aid us in the development of culturally sensitive training materials, and in the identification of potential trainers and family caregivers.

We have already talked by phone (with a few exceptions) in order to set the date on your calendar. If your plans have changed or if you have any questions, please call either of us at 804/786-1525. We are looking forward to working collaboratively with you in meeting the caregiving needs of the persons we serve in our communities.

Sincerely,

Constance L. Coogle, Ph.D.

Ruth B. Finley, M.S.

Enclosure



August 18, 1993

Dear Dr.

This letter is to request your cooperation on a project that we are conducting for the federal Administration on Aging. In October, 1992 the Virginia Center on Aging obtained funding to help rural and/or African-American families in Central and Southside Virginia who care for loved ones with Alzheimer's Disease or related dementias. has been an active member of our advisory group (or Regional Needs and Resources Team) in Southside since the beginning of this project. We feel that the involvement of the local Community Services Boards will be an important factor contributing to the success of our project. Since she is no longer able to actively participate on this project, we are requesting a replacement to provide representation to our advisory group. This representative would be asked to attend only a few regional meetings before the project concludes. Next month, we will be asking final approval of our training materials from the Regional Needs and Resources Teams prior to the commencement of training. The groups will be convened on an ad hoc basis thereafter, if we encounter any difficulties securing appropriate levels of participation.

had also agreed to be a trainer of caregivers and we are sorry that she can not follow through in that capacity. If anyone else on your staff might be interested in participating in the training we will offer and then, in turn, conducting a short series of caregiver workshops, please have them contact us for more information. The time commitment is not inordinate, requiring only 12-16 hours of training and then conducting approximately three workshops of two-three hours in length for a minimum of 10 family caregivers. The planned training will be quite informative, with immediate service applicability, especially with regard to African-American and rural community outreach.

We have identified 125 potential trainers to date and continue to seek individuals who are knowledgeable of aging, caregiver issues, or Alzheimer's Disease. We are also seeking to engage trusted community leaders (e.g., mental health professionals) who can encourage the involvement of family caregivers. In addition to trainers, we have identified 50 "caregiver contacts" or "access resources". These are individuals who have agreed to help our trainers find their required complement of 10 family caregivers. If you know of anyone who may be aware of family members who could take advantage of the workshops to be offered, please share the information about our project with them and ask them to call us.



We have enclosed a summary of our project and a list of the members of the Southside Regional Needs and Resources Team (i.e., the advisory group for which we are asking representation from your organization). We have also enclosed a flyer to help in recruiting other appropriate trainers for our project. Please post it in an appropriate location where potential trainers may frequent. Let us know if we can send you multiple copies for distribution among your associates who may be (or know of) appropriate trainers to assist in our project.

In closing we would like to commend to you for the excellent assistance she has provided. We look forward to continuing our relationship with your organization through the appointment of a replacement to our advisory group and/or staff participation in our training. If you have any questions or would like more information about our project, please contact Ruth Finley or Constance Coogle at the Virginia Center on Aging at (804) 786-1525. Thank you in advance for your cooperation on this project.

Sincerely,

Ruth B. Finley, M.S. Project Co-Director

Constance L. Coogle, Ph.D. Project Co-Director

Enclosures:

Project summary

Roster of Southside RNRT members

Trainer Recruitment flyer



# RESPONSES TO TELEPHONE INQUIRY

#### **IMPRESSIONS**

Most participants indicated a desire to continue to participate in the Regional Needs and Resources Team (RNRT) in "Assisting Caregivers of African-American and Rural Elders with Dementia." The following is a list of the response that were obtained from follow up telephone conversations from a sample of participants in the first meeting of the RNRT meeting. Other suggestions and comments are welcomed.

# Impressions of the meeting and project:

- \* Was not sure about what was suppose to take place when arriving, but had a clearer idea as to purpose when meeting was over.
- \* Was very impressed that rural and minority caregivers were target of the project.
- \* Fascinating idea to involve the community.

# Individuals expressed a willingness to

- \* identify trainers.
- \* be involved with the project, but at the present were unsure of total mission.
- \* be involved on the RNRT, but hadn't given much thought as to how their involvement could be of benefit.
- \* help identify barriers that rural and minority caregivers face.
- \* assist in whatever way Ruthie felt they would have the most impact
- \* think about ways of involvement because they had not really thought about issue since the meeting.
- \* be a trainer.
- \* offer the use of data bank on resources to include in caregiver resource manual.

# Suggestions to identify trainers:

- \* Specific names were given in many cases.
- \* Meals-on-Wheels volunteers.
- \* Contact more ministers or pastors in churches to reach members of the church family.
- \* Rural health personnel-public health nurses, physicians
- \* Members of the Board of Directors of the local Alzheimer's Association.
- \* Nursing homes and homes for adults.
- \* Support groups of the Alzheimer's Association.
- \* Advertise in local papers or Alzheimer's Association newsletter.
- \* Adult Protective Services
- \* Flyer to publicize Community Service Boards.

# Suggestions to identify others persons for the RNRT:

- \* Richmond Mental Health
- \* Members of the Board of Directors of the local Alzheimer's Association.
- \* There needs to be more black representation.
- \* Consumer representation is felt to be needed.



Participants were interested in devoting time to edit modules of the resource manual for cultural sensitivity. There was a strong request to keep the manual as simple as possible. Several concerns were expressed that the manual may become too academically focused.

#### Other comments:

- \* Felt that more involvement is needed from the RNRT, but felt that many did not understand what the meeting was for.
- \* Liked the train-the-trainer model to assist caregivers of rural and minority elders with dementia with the one-to-one involvement.
- \* Hadn't really had time to think about issues, but will certainly give it some thought.
- \* Still confused, but should clear up as project further develops.
- \* Felt as if there was a broad representation of people to help reach caregivers.
- \* Agreed that the train-the-trainer model would be acceptable way of reaching caregivers as many people are resistant to people coming into their home that they don't know.
- \* Interest in the suggestions of others and would like to have feedback of calls.
- \* Glad the focus was on Afican-Americans, because black people are people too.
- \* Need for a glossary of common words associated with caregiving of individual with Alzheimer's Disease.
- \* Very good and informative meeting.
- \* A service that is needed badly have been identified.
- \* There was a lot of diverse ideas as to the purpose of the meeting and the project.
- \* Some educators felt that they knew how to address the issue of the barriers faced by African-American caregivers.
- \* Concerned that the focus became on identifying minorities.
- \* Should remember that not everyone has a VCR to view resource tape.
- \* Train-the-trainer model may be too intimidating for some in trying to reach quotas.
- \* Felt there was a confusion of the mission and what was purpose.
- \* Caregivers need education.
- \* Thanks for calling for suggestions.



# REGIONAL NEEDS AND RESOURCES TEAMS QUESTIONNAIRE

The questions which follow pertain to the Virginia Center on Aging's project to educate family caregivers of rural and/or African American elders with dementia. Please take a few minutes to respond to the questions which follow. Your suggestions and advice are very important to us, so please take a few moments now, while you have the questions in front of you.

- 1. How successful was the nominal group process in helping us identify important training topics and information useful to family caregivers? (Circle one response)
  - 0 = Could not attend meeting
  - 1 = Not Very Successful
  - 2 = Somewhat Successful
  - 3 = Very Successful

|       | nentioned on the enclosed list of results, that should be included in the training culum? If yes, what other information or topics should be included?   |
|-------|--|
|       | you interested in being a trainer of caregivers for this project? If yes, what are you   |
| careg | fications? Remember: we are looking for individuals who are knowledgeable giver issues and informational needs, connected with caregiver networks local apable of recruiting potential caregiver trainees. |



|   | •  |
|---|--|
| Yes                                     | No   |
|   | s to minority or rural caregivers who could benefit es, who are they and how may we contact them?  |
|   | ng a training module in your particular area of s or caregivers? If yes, what topic area?  |
| particular area of expertise for use in | interested in developing a training module in their raining the trainers or family caregivers? If yes, em, and what is their area of expertise?  |
|   |  |
| •                                       | editing the training curricula developed to insure sitive, and literacy appropriate?   |
| Yes                                     | . No   |
|   | Do you know of others who have access from the educational workshops? If ye would you be interested in developing expertise for use in training the trainers.  Do you know of others who would be it particular area of expertise for use in twho are they, how may we contact the who are they, how may we contact the would you be interested in reviewing/that it is comprehensive, culturally sent |



#### **MINUTES**

#### of the

# SOUTHSIDE REGIONAL NEEDS AND RESOURCES TEAM

The initial meeting of the Southside Regional Needs and Resources Team (RNRT) was held at the Southside Virginia Community College in Keysville on Tuesday, December 15, 1992. After refreshments, project co-directors Constance Coogle and Ruth Finley called the meeting to order about 2:20 p.m. and welcomed the group. Woody Hanes of the Southside AHEC was thanked for handling the local arrangements for the meeting.

Self introductions were made, and those present were as follows (see list of members for affiliations): Carol Bottoms, John Cafazza, Sandra Carpenter, Frank Conteh, Ronald Dunn, James Gunnell, Woody Hanes, Maxcine Maxfield, F. C. Moody, Brigitte Pennington, Amelia Poythress, Allene Reece, Myrna Thompson, Johnnye Thompson, and Morag (Mo) Walden. Donna Coffman and Kay Beall from the Central RNRT were also present as were the following staff: Ed Ansello, Michael Pyles, and Jackie Moore.

Ruth Finley briefly described the 17 month training grant from the U. S. Administration on Aging in which the two RNRTs (Central and Southside) would assist in (1) identifying both needs and resources of rural and/or minority caregivers in their respective communities; (2) identify potential trainers to provide caregiver training; (3) identify potential caregivers for training. In addition, the RNRT's would recognize potential barriers to training and make suggestions on how to overcome them. Selected members would aid with curriculum development.

Ruth Finley also provided a brief overview on dementia (of which AD is the most common type) -- what it is (and is not), related disorders, reversible disorders, and diagnosis. Secondly she discussed the "second victim" - the caregiver -- and utilized a short video segment to initiate discussion about caregivers' feelings and cultural sensitivity (or lack of). Lastly she suggested how individuals, organizations, faith communities and projects such as this one can respond to meet the needs.

Michael Pyles detailed some of the unique issues which characterize the two underserved populations which this project will address: rural and/or minority caregivers. He discussed the fact that although there is often a large informal network of support for African American eldercaregivers, this does not completely protect them from caregiver strain. Their strong sense of duty makes it difficult for them to admit remorse or discomfort about the caregiver role.

Constance Coogle overviewed the operational aspects of the RNRT's and clarified misconceptions. The ultimate beneficiaries of the project will be caregivers; however, the trainers will benefit from the two day training which they will be provided as well as the



extensive directory of resources which will be developed. There will be no remuneration for trainers but expenses will be reimbursed. There will be no charge for caregiver training, and they will be given assistance with respite services and transportation if necessary.

Members of the Team offered various comments and insights and projected enthusiasm for the undertaking. The importance of picking appropriate training sites in order to place caregivers in the "comfort zones" was emphasized. The group also discussed the advisability of avoiding the word "problem" when approaching caregivers, since this can make them feel stigmatized. Members were asked to make suggestions about other representatives who would be appropriate additions to the Regional Needs and Resource Team.

Members offered various sites for future Regional Needs and Resource Team Meetings. The next meeting date was set by consensus: Thursday, February 4, 1993 at St. Paul's College, with local arrangements being handled by Dr. Gunnell.

The group adjourned about 4:20 p.m., and a number of individuals remained for continued dialogue with the staff.

Submitted by Ruth B. Finley



#### **MINUTES**

#### of the

#### CENTRAL REGIONAL NEEDS AND RESOURCES TEAM

The initial meeting of the Central Regional Needs and Resources Team (RNRT) was held at the Alzheimer's Association - Greater Richmond Chapter Office in Richmond on Wednesday, December 16, 1992. After refreshments, project co-directors Constance Coogle and Ruth Finley called the meeting to order about 2:20 p.m. and welcomed the group. Lynda Gormus, Patient and Family Services Coordinator for the Alzheimer's Chapter was thanked for handling the local arrangements for the meeting.

Self introductions were made, and those present were as follows (see list of members for affiliations): Jean Cobbs, Charlotte Crawford, Joy Duke, Lynda Gormus, Otis Johnson, William Johnson, Linda King, Marjoria (Jo) Martin, Leslie Miles, Marie Moore, Virginia Tyack, Robert Pettis, Dottie Schick, Jacob Singer, and Jodi Teitelman. The following staff: Ed Ansello, Michael Pyles, and Jackie Moore.

Ed Ansello, Director of the Virginia Center on Aging, briefly described the 17 month training grant from the U. S. Administration on Aging in which the two RNRTs (Central and Southside) would assist in (1) identifying both needs and resources of rural and/or minority caregivers in their respective communities; (2) identify potential trainers to provide caregiver training; (3) identify potential caregivers for training. In addition, the RNRT's would recognize potential barriers to training and make suggestions on how to overcome them. Selected members would aid with curriculum development.

Ruth Finley provided a brief overview on dementia (of which AD is the most common type) and described caregivers as the "second victim" of the disease. She utilized a short video segment to initiate discussion about caregivers' feelings and cultural sensitivity (or lack of). Lastly she suggested how individuals, organizations, faith communities and projects such as this one can respond to meet the needs.

Michael Pyles detailed some of the unique issues which characterize the two underserved populations which this project will address: rural and/or minority caregivers. He discussed the fact that although there is often a large informal network of support for African American eldercaregivers, this does not completely protect them from caregiver strain. Their strong sense of duty makes it difficult for them to admit remorse or discomfort about the caregiver role. He discussed differences in the cultural view of dementia and commented on the lack of knowledge and resources among the target populations. Issues of distrust and the essential nature of good communication skills were also mentioned.



Constance Coogle overviewed the operational aspects of the RNRT's and clarified misconceptions. The ultimate beneficiaries of the project will be caregivers; however, the trainers will benefit from the two day training which they will be provided as well as the extensive directory of resources which will be developed. There will be no remuneration for trainers but expenses will be reimbursed. There will be no charge for caregiver training, and they will be given assistance with respite services and transportation if necessary.

Members of the Team offered various comments and insights and projected enthusiasm for the undertaking. Members were asked to make suggestions about other representatives who would be appropriate additions to the Regional Needs and Resource Team.

Members were asked to suggest sites for future Regional Needs and Resource Team Meetings. The next meeting date was set by consensus: Tuesday, February 2, 1993 at Zion Baptist Church, with local arrangements being handled by Rev. Pettis.

The group adjourned about 4:20 p.m., and a number of individuals remained for continued dialogue with the staff.

Submitted by Ruth B. Finley



### **MINUTES**

#### of the

## CENTRAL REGIONAL NEEDS AND RESOURCES TEAM

The second meeting of the Central Regional Needs and Resources Team (RNRT) was held at the Zion Baptist Church in Richmond on Tuesday, February 2, 1993. After refreshments, project Co-Directors Constance Coogle and Ruth Finley called the meeting to order at approximately 1:15 p.m. and welcomed the group.

Copies of the revised roster of members in the Central RNRT were distributed and self introductions were made. Those present were as follows: Vivian Bagby, Faye Cates, Charlotte Crawford, Joy Duke, William Jackson, Beatrice Johns, Otis Johnson, Linda King, Marjoria (Jo) Martin, Leslie Miles, Herbert Plummer, Isaac Ridley, Jacob Singer, Jodi Teitelman, Elizabeth Turf, and Virginia Tyack. Terri Hardin of the Southside RNRT was also present. Ms. Finley introduced Melissa Ferrell (new project staff member) and Joan Wood (project consultant).

Ms. Finley briefly reiterated the nature of the project, summarized the highlights of the group's initial meeting, and distributed a hand-out detailing the results of follow-up phone calls made to Team members by Jackie Moore. Team members had expressed a definite interest in the project and a concerted willingness to help achieve project goals. Members had also offered various suggestions about mechanisms through which trainers may be identified, and in some cases the names of individuals who would be interested in participating as trainers had been given. There was a general consensus that the composition of the Teams was satisfactory, although some had felt that family caregivers should be included as members of the RNRT. Vocabulary lists prepared to assist members unfamiliar with aging terminology were distributed along with lists of the area agencies on aging in Virginia.

Ms. Finley distributed a sample training module entitled "Managing Episodes of Aggressive Behavior", and briefly described its format. She emphasized the advantages of including a mini-lecture rather than an outline and reinforcing the information presented with audio-visual materials and experiential learning exercises. She also pointed to the importance of designating how audio-visual resources can be accessed and providing a suggested reading list. Team members were asked to review and edit the sample training module and return it to the project staff. Joy Duke volunteered to serve on the Curriculum Review Committee.

Dr. Coogle distributed copies of instructions for the nominal group process. She asked Team members to take a few minutes to think about the educational needs of caregivers of dementia patients, with a particular emphasis on the unique aspects of African American and rural caregiving situations. There was a brief discussion of the barriers that may be encountered when trying to recruit caregivers and the importance of working through the churches to encourage African American participation. The results of the nominal group process are



enclosed. The content areas identified were, in rank order: emotional and psychological consequences of caregiving, caregiver supports, basic clinical information, safety, and legal/financial issues.

Ms. Finley led the group in a discussion of ways to overcome barriers to caregiver participation in workshops. A number of issues were discussed including: (1) caregiver attitudes stemming from feelings of pride, shame, denial, and the ethic of independence; (2) pragmatic considerations such as transportation, respite care, scheduling, location, programming, format, and marketing; (3) the advantage of working with community residents (e.g., barbers, grocers, beauticians, midwives, physicians, police, funeral directors), as well as public health nurses, congregate meal site workers, and neighborhood association leaders, when recruiting caregivers; and (4) employing incentives such as providing an atmosphere of caring with peers, stressing the need for information, and serving refreshments or tying into a "pot luck" meal after church. The group commented that community-based services in rural areas have not existed historically. It was pointed out that educational outreach efforts to the African American community have traditionally derived from work with other minority groups, and the importance of addressing the unique needs of African American family caregivers was emphasized. The trainer team approach was commended, realizing that sanction from the local community was needed but also understanding that training expertise could come from outside the community. The group concluded that pairing trusted community leaders with those who are effective and knowledgeable trainers would be ideal.

Ms. Grace Archer of the Zion Baptist Church was thanked for hosting the meeting. The group adjourned about 4:10 p.m., and a number of individuals remained for continued dialogue with the staff.

Submitted by Constance L. Coogle



#### **MINUTES**

#### of the

### SOUTHSIDE REGIONAL NEEDS AND RESOURCES TEAM

The second meeting of the Southside Regional Needs and Resources Team (RNRT) was held at Saint Paul's College in Lawrenceville on Thursday, February 4, 1993. Dr. James Gunnell, Vice President for Academic Affairs for the College introduced himself and Dr. Frank Conteh, Chairman of the Department of Humanities and Behavioral Sciences, who welcomed the group on behalf of the President of Saint Paul's College, Dr. Thomas Law. Dr. Conteh then introduced Reverend Deborah Ellison, who said grace over the lunch which was generously provided by the College. After lunch, project Co-Directors Constance Coogle and Ruth Finley thanked Dr. Gunnell and the College for providing lunch and called the meeting to order at approximately 1:15 p.m.

Attendees received a revised roster of members in the Southside RNRT and self introductions were made. Those present were as follows: Sandra Carpenter, Frank Conteh, Deborah Ellison, Ed Fisher, James Gunnell, Woody Hanes, Jim Jackson, Karen Jones, Carol-Ann Lawson, Maxcine Maxfield, Brigitte Pennington, Amelia Poythress, Myra Quick, Myrna Thompson, Johnnye Thompson, and Morag (Mo) Walden. Donna Coffman, Marie Moore, and Delores Dungee-Anderson from the Central RNRT were also present, as were the following staff: Ed Ansello, Michael Pyles, and Joan Wood.

Ms. Finley briefly reiterated the nature of the project and summarized the highlights of the group's initial meeting and the results of follow-up phone calls made to Team members. Team members had expressed a definite interest in the project and a concerted willingness to help achieve project goals. Members had also offered various suggestions about mechanisms through which trainers may be identified, and in some cases the names of individuals who would be interested in participating as trainers had been given. Some members had expressed concerns that there was still some confusion about the purpose and mission of the project. There was a general consensus that the composition of the Teams was satisfactory, although some felt that African Americans were under-represented. In response to advice offered at the last meeting, the Co-Directors had prepared vocabulary lists to assist members unfamiliar with aging terminology, and lists of the area agencies on aging in Virginia were also distributed.

Ms. Finley briefly described the sample training module entitled "Managing Episodes of Aggressive Behavior". She emphasized the advantages of including a mini-lecture rather than an outline and reinforcing the information presented with audio-visual materials and experiential learning exercises. She also pointed to the importance of designating how audio-visual resources can be accessed and providing a suggested reading list. Team members were asked to review and edit the sample training module and return it to the project staff.

Dr. Wood conducted the nominal group process to identify the educational needs of



caregivers. The results of the nominal group process are enclosed. The content areas identified were, in rank order: disease and treatment, patient behaviors and interventions, impact on caregivers and families, caregiver interventions, resources, legal/financial/patient competency, and placement options/continuum of care.

Dr. Ansello led the group in a discussion of ways to overcome barriers to caregiver participation in the planned workshops. A number of issues were discussed including: transportation, scheduling, the importance of trainers gaining the trust and confidence of family caregivers, respite care, the importance of respite caregivers gaining the trust of family caregivers, problems associated with illiteracy and functional illiteracy, the advisability of using visual aids, racial sensitivity, male chauvinism, and ethical considerations.

The group adjourned about 4:20 p.m., and a number of individuals remained for continued dialogue with the staff.

Submitted by Constance L. Coogle



# SAMPLE PRESS RELEASE

### USE AS A GUIDE

PRESS RELEASE: FOR IMMEDIATE PUBLICATION

DATE: (FILL IN THE DATE WHEN YOU ARE TAKING THIS TO MEDIA CONTACTS)

CONTACT: (YOUR NAME)

PHONE: (PLEASE USE A DAYTIME PHONE NUMBER)

VIRGINIA CENTER ON AGING AT MCV/VCU TO OFFER COMMUNITY INFORMATION SESSION FOR RURAL AND/OR MINORITY CAREGIVERS OF ELDERS WITH DEMENTIA

An innovative program to educate rural and/or African American family members caring for elders with Alzheimer's Disease and other dementias will be offered by the Virginia Center on Aging at the Medical College of Virginia/Virginia Commonwealth University. The project, which is supported in part by the U. S. Administration on Aging, will be offered in local communities in Central and Southside Virginia.

The program consists of a series of workshops designed to help families learn more about Alzheimer's Disease (or other dementias) and the community resources available to support them. The workshops will be organized to correspond with the progressive nature of dementia, so that caregivers can get the information they need, when they need it. Some of the topics that will be covered are medications and treatment, legal and financial issues, personal care skills, dealing with communication and behavior problems, safety and environmental adaptations, and caring for the caregiver.

Anyone interested in participating in the workshops should call

(YOUR NAME) at (YOUR PHONE NUMBER)

(NOTE TO EDITORS: A COPY OF AN EARLIER PRESS RELEASE CONCERNING THE PROJECT IS ATTACHED. PLEASE FEEL FREE TO CONTACT PROJECT CO-DIRECTORS RUTH FINLEY OR CONSTANCE COOGLE AT (804) 786-1525 IF YOU WOULD LIKE ADDITIONAL INFORMATION.)



# Greater Richmond Chapter President and Secretary Receive Grant to Help Rural and Minority Caregivers in Central and Southside Virginia

The President (Ruth Finley) and Secretary (Constance Coogle) of the Alzheimer's Association - Greater Richmond Chapter have received funding from the federal Administration on Aging to help family caregivers in the Southside and Central Virginia Alzheimer's Association territories. Their grant proposal, "Assisting Caregivers of Black and Rural Elders with Dementia", which was submitted through the Virginia Center on Aging, will deliver caregiver workshops targeted to rural and minority families caring for elders with dementia.

The project staff will work with majority and minority institutions of higher education to create Regional Needs and Resources Teams with representation from the <u>Greater Richmond and Southside Chapters of the Alzheimer's Association</u>, various State departments and groups, churches, area agencies on aging, and other local service agencies. These planning groups will guide the development of training materials and identify trusted community leaders who will recruit caregivers and be trained to conduct the caregiver workshops.

For further information contact Ruth Finley or Constance Coogle at the Virginia Center on Aging, (804) 786-1525.



# JOINING FORCES WITH AFRICAN AMERICAN AND RURAL COMMUNITY LEADERS: LOOKING FOR A FEW GOOD TRAINERS

More than 20,000 individuals in Central and Southside Virginia suffer from Alzheimer's Disease and other dementias. The Virginia Center on Aging is looking for individuals interested in providing education to African American and/or rural families caring for persons with Alzheimer's Disease and other dementias.

In cooperation with the Virginia Geriatric Education Center with funding from the federal Administration on Aging, trusted community leaders, human services providers, and other individuals familiar with family caregivers and caregiving issues will receive two full days of free, expert training in early fall. Trainers will form two-person teams and conduct local caregiver workshops for a minimum of 10 family caregivers in their communities. Trainers will be given detailed instruction manuals to guide them in planning and delivering the educational seminars. Both trainers and caregivers will receive a resource directory of national, state, and local services.

This project, under the direction of Dr. Connie Coogle and Ms. Ruth Finley is now in its third quarter. Working in the cities, townships and counties served by two Alzheimer's Chapters-Greater Richmond and Southside Virginia--the co-directors have assembled two Regional Needs and Resources Teams for input and editing of training materials, solicitation of appropriate trainers, and facilitation of the delivery of training to caregivers of dementia family members in rural areas and/or African American families. As we go to press, 89 potential trainers and 22 individuals who can encourage caregiving participation have been identified.

More trainers are being solicited to participate in the thorough two-day "train-the-trainer" program in the fall. Participants will receive a training manual which includes modules organized to correspond to the progression of dementia. In addition to the training modules, the manual will include: 1) a section outlining the purpose and rationale of the grant project, a description of the target audience, and the content contained therein; 2) basic information about dementia and Alzheimer's Disease. and an overview of relevant caregiver issues; 3) a chapter on adult learning theory; 4) an in depth discussion of cultural issues relevant to African-American caregivers, the barriers to service among that population, and ways of overcoming those barriers; 4) a similar section sensitizing trainers to rural issues; and 5) a pragmatic, user-friendly section includes step-by-step instruction on planning and conducting caregiver workshops, appropriate use of the training materials to accommodate the needs of caregiver trainees, and details important to evaluating training effectiveness. A resource directory will be provided on diskette to allow for updating.

If you are interested in becoming a trainer or can encourage caregivers to participate contact Ruth Finley or Constance Coogle at 804/786-1525, Virginia Center on Aging, Virginia Commonwealth University, Box 229, Richmond, VA 23298.



January 14, 1993

Dear Member of the Virginia Baptist General Board:

The Virginia Center on Aging has obtained funding from the U. S. Administration on Aging to improve eldercare services for rural and minority dementia patients in Central and Southside Virginia. The overall goal of the project, entitled "Assisting Caregivers of Minority and Rural Elders with Dementia," is to identify rural and/or minority family members providing care for elders with dementia and provide information to help them become more effective caregivers. The project has formed regional planning groups with representatives from organizations that can outreach to these caregivers, e.g., government agencies, colleges and universities, the Alzheimer's Association, churches, and others. These planning groups, called Regional Needs and Resources Teams, will advise the project staff and assist in recruiting trainers who are knowledgeable of caregiver issues and informational needs, connected with caregiver networks locally, and capable of recruiting potential caregiver trainees. In addition, the Teams will guide the development of the training curriculum, helping to identify the needs of these caregivers and ensuring the use of appropriate and culturally sensitive materials.

The success of our project will depend in part on the goodwill and cooperation of trusted community leaders, especially those who are active in the church. Our goal is to reach out to caregivers who have been reluctant to utilize formal services. Since many of these individuals have turned to the church for help, religious leaders are in a unique position to help us identify those who could benefit from the education we will offer.

A news release announcing the project is attached to this letter. If you think you might be an important addition to our Regional Needs and Resources Teams, know someone who might be, or could help in our efforts to identify appropriate trainers and caregiver trainees, please contact Constance Coogle or Ruth Finley at the Virginia Center on Aging at (804) 786-1525. Please share this information with others who, in your estimation, would significantly contribute to the work of this group. Thank you in advance for your interest and assistance.

Sincerely,

Ruth B. Finley, M.S. Project Co-Director

Constance L. Coogle, Ph.D. Project Co-Director



### January 14, 1993

Dear Member of the Virginia Council of Churches:

The Virginia Center on Aging has obtained funding from the U. S. Administration on Aging to improve eldercare services for rural and minority dementia patients in Central and Southside Virginia. The overall goal of the project, entitled "Assisting Caregivers of Minority and Rural Elders with Dementia," is to identify rural and/or minority family members providing care for elders with dementia and provide information to help them become more effective caregivers. The project has formed regional planning groups with representatives from organizations that can outreach to these caregivers, e.g., government agencies, colleges and universities, the Alzheimer's Association, churches, and others. These planning groups, called Regional Needs and Resources Teams, will advise the project staff and assist in recruiting trainers who are knowledgeable of caregiver issues and informational needs, connected with caregiver networks locally, and capable of recruiting potential caregiver trainees. In addition, the Teams will guide the development of the training curriculum, helping to identify the needs of these caregivers and ensuring the use of appropriate and culturally sensitive materials.

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A news release announcing the project is attached to this letter. If you think you might be an important addition to our Regional Needs and Resources Teams, know someone who might be, or could help in our efforts to identify appropriate trainers and caregiver trainees, please contact Constance Coogle or Ruth Finley at the Virginia Center on Aging at (804) 786-1525. Please share this information with others who, in your estimation, would significantly contribute to the work of this group. Thank you in advance for your interest and assistance.

Sincerely,

Ruth B. Finley, M.S. Project Co-Director

Constance L. Coogle, Ph.D. Project Co-Director





The Reverend Jim Jackson, President of the Alzheimer's Association - Southside Virginia Chapter, suggested that we contact you about our project to identify and educate rural and/or minority family members providing care for elders with dementia. In October, 1992 the Virginia Center on Aging obtained funding from the U. S. Administration on Aging to help families in Central and Southside Virginia who care for loved ones with Alzheimer's Disease or related dementias.

We are currently in the process of identifying individuals who are knowledgeable of caregiver issues and informational needs, connected with community resources, and dedicated to sharing their knowledge with parishoners and others who are caregivers. Later this year, we will train these individuals to provide sensitive and compassionate education for family members interested in becoming more effective caregivers. Trained pastors and other trusted community leaders will then go into their respective communities and conduct several local workshops (approximately 2-4 hours in length).

The success of our project depends in part on the goodwill and cooperation of trusted community leaders, especially those who are active in the church. Our goal is to reach out to caregivers who have been reluctant to utilize formal services. Since many of these individuals have turned to the church for help, religious leaders are in a unique position to help us identify those who could benefit from the education we will offer.

If you could help in our efforts to identify ppropriate trainers and caregiver trainees, please contact Constance Coogle or Ruth Finley at the Virginia Center on Aging at (804) 786-1525. Please share this information with others who, in your estimation, would significantly contribute to the work of this group. Thank you in advance for your interest and assistance.

Ruth B. Finley, M.S.

of B Finley

Project Co-Director

Sincerely,

Constance L. Coogle, Ph.D.

Project Co-Director

Virginia Center on Aging ● 520 North 12th Street ● MCV ● Box 229 ● Richmond, Virginia 23298-0229 (804) 786-1525 ● VOICE TDD (804) 786-0956 ● FAX (804) 225-3299



Immaculate Heart of Mary Church 919 S. Main St. (P.O. Box 266) Blackstone, VA 23824 292-5535 or 478-4525 St. John's Church 102 Oliver Avenue Crewe, VA 23930 645-7509 or 478-4525 Sacred Heart Church Route 728 (P.O. BOx 62) Meherrin, VA 23954 736-9390 or 478-4525

Therese Ann Mansfield, Pastoral Coordinator

Twenty-First Sunday in Ordinary Time

Rev. Anthony Dinges, Celebrant

August 22, 1993



In today's GospelJesus' question, "Who do people say that the Son of Man is?", is directed to all is disciples. The disciples respond with what must have been the identity given by the people in the area. People think of Him as great, perhaps a prophet, John the Baptizer. Jesus asks them to express their own faith.

t is Peter who answers most profoundly. Peter, the leader, know who Jesus is. He identifies esus as God's son, His annointed one.

esus responds to his faith by giving him a new name and a new role. Peter recognizes who Jesus s and accepts Him. Like the baptized, his new name symbolizes his new life and mission. Peter s the foundation of the new building created through faith in Jesus Christ.

eter will have authority over who enters and leaves the church. Jesus gives Peter the power to udge.

he reading ends with Jesus' command to refrain from telling anyone who He is. This may reflect he belief that only after Jesus' death and resurrection could his real identity be known. effect on today's Gospel. Who do you say Jesus is? If you say that Jesus is the Son of God, that does that mean in your life? Does it make any difference?

ATHOLIC LAWYER'S LITURGY AND BREAKFAST: The St. Thomas More Society will sponsor continental reakfast at 7:00 a.m. Wednesday, September 8 at the Holiday Inn at 3207 North Boulevard, Richmo he speaker will be Fr. Michael Maruca, SJ, Sacred Heart Parish, S. Richmond. Cost: \$5.00 for reakfast. All Catholic lawyers, judges and law students are invited.

OMMUNITY INFORMATION WORKSHOPS FOR RURAL FAMILIES CARING FOR LOVED ONES WITH ALZHEIMER'S DISEAS R OTHER DIMENTIAS: Free community workshops will be offered in our area this Fall. To learn ore about caring for loved ones with these problems, please contact:

Virginia Center on Aging, Medical college of Virginia

Virginia Commonwealth University Box 229

Richmond, VA 23928-0229

(804) 786-1525 (Ask for Dr. Connie Coogle or Ms. Ruth Finley)

inancial aid may be available for transportation and arranging for adult sitters.



The and fifth on Concernation will donner a total of

BEST COPY AND A PLANT



# Medical College of Virginia Virginia Commonwealth University

# Dear Community Leader:

Last fall you may have received a press release announcing the Virginia Center on Aging's grant from the U.S. Administration on Aging to train rural and/or African American family caregivers of persons with dementia (e.g., Alzheimer's Disease). We have enclosed a project description to give you more information about this effort. To date, more than 100 trainers have been recruited to take part in an intensive two-day training course. They will conduct a series of workshops in their communities to share their knowledge with at least 10 family caregivers.

In order for your clients, patients, members, etc. who are appropriate for this training to receive information about when and where the training will be offered in their areas, please ask their permission for you to send us their names, addresses and phone numbers. A form and address label have been enclosed for your use. The caregivers will be contacted by a trainer in their area and encouraged to attend the workshops. The family caregiver training will be approximately 10-12 hours, spread out over several sessions. Workshop topics will include basic information about the disease, available resources and services to help them as the disease progress, and practical instruction on how to provide better care. There is no charge to participants, and we can provide some assistance with arranging transportation and adult care if necessary. We have also enclosed a recruitment flier for publicizing the caregiver workshops. Please post in a key location where family caregivers will see it. You have no idea what a tremendous service you will be providing by helping caregivers to help themselves through the educational sessions.

If you or the caregivers you contact have any questions, please do not hesitate to call either of us at 804/786-1525. Thank you for your assistance.

Sincerely yours,

Constance L. Coogle, Ph.D.

Ruth B. Finley, M.S.

enclosures:

Recruitment Fliers

Project Description Form for Names Address Label

Virginia Center on Aging ● 520 North 12th Street ● MCV ● Box 229 ● Richmond, Virginia 23298-0229 (804) 786-1525 ● VOICE TDD (804) 786-0956 ● FAX (804) 371-7905





TO:

Members of the Alliance for Black

Social Welfare, Inc.

FROM:

Connie Coogle, Ph.D and Ruth B. Finley, M.S.

Project Co-Directors

DATE:

October 8, 1993

The Virginia Center on Aging received funding from the United States Administration on Aging to develop an innovative program to educate family members caring for elders with Alzheimer's Disease and other dementias. (See project description enclosed.) Outreach is particularly targeted to African-American families and churches in the metro Richmond are as well as to rural families in Southside Virginia.

The educational sessions for families will be conducted in individual communities by "trusted resources," whether professional or volunteer, who have participated in an extensive two-day training provided by the Virginia Center on Aging. The two-day training sessions will be offered four times as shown on the enclosure (blue).

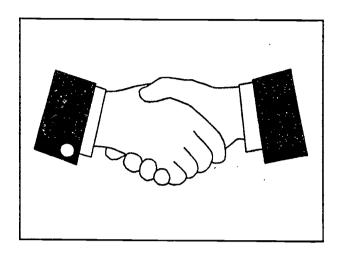
There are several ways in which you can contribute to the success of these community based educational workshops. First and most importantly, "spread the word" in your community to African-American families who are caring for a loved one with dementia by being an "access person"....that is, tell families to contact us directly or you can act as the conduit to supply information to them. Obtain permission from families before sending us their names and addresses and phone numbers, if they wish you to do so.

Secondly, we are recruiting minority trainers. The only requirement to receive two full days of high quality training (CEU's will be offered), a training manual and a resource directory is to recruit and share caregiving education with 10 volunteer caregivers who provide care to someone with dementia. Trainers are urged to "pair up" and work as a team in recruitment and facilitating the community workshop sessions as soon as possible after completion of the two-day training. If you are interested in being a trainer, please fill out the enclosed registration form (salmon) and mail (address label enclosed) or FAX 804-371-7905 it to us immediately. The first set of training dates are October 22-23 at Keysville. Directions to the four sites are enclosed (yellow) as well as the tentative agendas (green).



Virginia Center on Aging ● 520 North 12th Street ● MCV ● Box 229 ● Richmond, Virginia 23298-0229 (804) 786-1525 ● VOICE TDD (804) 786-0956 ● FAX (804) 371-7905

# JOINING FORCES WITH AFRICAN AMERICAN AND RURAL COMMUNITY LEADERS



# LOOKING FOR A FEW GOOD TRAINERS

More than 20,000 individuals in Central and Southside Virginia suffer from Alzheimer's Disease and other dementias. The Virginia Center on Aging is looking for individuals interested in providing education to African American and/or rural families caring for persons with Alzheimer's Disease and other dementias.

In cooperation with the Virginia Geriatric Education Center with funding from the federal Administration on Aging, approximately 60 trusted community leaders, human services providers, and other individuals familiar with family caregivers and caregiving issues will receive two full days of free, expert training in late summer/early fall. Trainers will form two-person teams and conduct local caregiver workshops for a minimum of 10 family caregivers in their communities. Trainers will be given detailed instruction manuals to guide them in planning and delivering the educational seminars. Both trainers and caregivers will receive a resource directory of national, state, and local services.

Join forces today and help provide better quality care for those with Alzheimer's disease or other dementias. For more information contact Ruth Finley or Constance Coogle at (804) 786-1525, Virginia Center on Aging, Virginia Commonwealth University Box 229, Richmond, VA 23298.





# SUGGESTIONS FOR A SUCCESSFUL OUTREACH PROGRAM IN AFRICAN AMERICAN COMMUNITIES

Adapted from material provided by Edna Ballard, Duke University Alzheimer's Disease Research Center

1. Ethnicity matters - people are equal but different. Learn as much as you can about cultural differences in history, tradition, and health practices.

Be mindful of social expectations or behaviors which may offend older African Americans. Use last names and proper titles. Avoid labels such as "non-white".

Be prepared to offer help to caregivers on their own terms and address what they feel are the important problems. Families want professionals to be competent, knowledgeable, and sensitive about the difficulties they are facing. Respect their approach to working with their loved ones.

2. People generally do not respond to information about services until they reach the "point-of-pain" - that point where their situation becomes painful enough to require action.

Try to impress upon them the importance of being prepared for what is to come and the value of knowing what they can do before a crisis situation arises.

3. A major barrier to service use in the minority community is a lack of familiarity with services and providers and/or a lack of trust in the agencies providing services. Trust is a critical element in the decision to use service.

Allow families to explore their fears, questions, misgivings, etc. Explain that the workshops will be planned to meet their specific needs. Never promise what you can't deliver and always deliver what you promise.

4. Another barrier is the cultural "sacred cows", which make service use incompatible with beliefs and values of the individual, for example, "we take care of our own." Being helpful in these instances requires understanding the cultural "musts" and "must nots" of the group and offering service in a way which becomes acceptable.

Let the caregivers know that you have an understanding of their traditions, values and beliefs. Offer help in a manner that is acceptable to the family. Inform them that the workshops are designed to be useful to families in African American communities.



5. Practical considerations often have important consequences. Creativity and flexibility about when and where services are offered may increase participation.

Let the families know that you intend to offer the workshops at a place and time that is convenient for those attending.

6. Families often do not define themselves as "caregivers."

Be mindful of jargon or words which may not be familiar, for example, "caregivers." Refer instead to families who care for an older relative or family member.

7. Families may not be aware that their care recipients may have Alzheimer's Disease or another dementia. Multi-infarct stroke is a common cause of dementia among African Americans.

Refer instead to behavioral symptoms such as memory loss, mood changes, judgment difficulties, and temperamental outbursts.

8. There are many different kinds of families in the African American community, including persons unrelated or distantly related by blood or marriage who are nonetheless considered to be family or primary caregivers. For example, grandchildren often willingly assume primary care.

Focus on the caregiving needs of the family. The "kind" of family is irrelevant except, where there is a question of legal authority in making decisions for the person with Alzheimer's Disease.

9. The primary caregiver may be reluctant to participate in the workshops, especially if the patient or other family members object. Some family members may feel that the workshops are unnecessary, particularly in the early stages when the patient's problems are not obvious.

Be supportive of the caregiver's decision to participate, despite objections from others. It helps to remind the caregiver that there are "no right or wrong answers" for many caregiving dilemmas. The caregivers must decide what is best for themselves.

10. People who are unserved deserve to be reached. It is important to communicate the benefits of caregiver education. Some caregivers may believe that Medicare will pay for everything.

Explain the benefits of workshop participation and why they need to know about supportive community services. Let them know that some service agencies are making special efforts to serve minorities better by training personnel to be knowledgeable of cultural considerations.



# SUGGESTIONS FOR A SUCCESSFUL OUTREACH PROGRAM IN RURAL COMMUNITIES

1. The rural elderly are typically underserved. As a consequence, caregiving families may be suspicious of offers to help.

Allow families to explore their fears, questions, misgivings, etc. Fxplain that the workshops will be planned to meet their specific needs. Never promise what you can't deliver and always deliver what you promise.

2. Isolated, rural families may believe that they can't do anything to improve their caregiving situation. They may think that the situation is unchangeable, for example, "It's all in God's hands."

Emphasize the benefits of workshop participation and why they need to know about supportive community services. Families need to become empowered and learn that they can exert control over their lives.

3. Rural families tend to be less educated. Non-scientific views of health and illness are not uncommon. Religious traditions, local folklore, and reliance on herbal medicines may all be barriers to adequate health care.

Be prepared to offer help to caregivers on their own terms and address what they feel are the important problems. Respect their approach to working with their loved ones. Let the caregivers know that you have an understanding of their traditions, values and beliefs. Offer help in a manner that is acceptable to the family. Inform them that the workshops are designed to be useful to those in rural communities.

4. People generally do not respond to information about services until they reach the "point-of-pain" - that point where their situation becomes painful enough to require action.

Try to impress upon them the importance of being prepared for what is to come and the value of knowing what they can do before a crisis situation arises.

5. Practical considerations often have important consequences. Creativity and flexibility about when and where services are offered may increase participation.

Let the families know that you intend to offer the workshops at a place and time that is convenient for those attending.



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Refer instead to behavioral symptoms such as memory loss, mood changes, judgment difficulties, and temperamental outbursts.

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Be supportive of the caregiver's decision to participate, despite objections from others. It helps to remind the caregiver that there are "no right or wrong answers" for many caregiving dilemmas. The caregivers must decide what is best for themselves.

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Explain the benefits of the workshop participation and why they need to know about supportive community services.



# HOW TO RECRUIT CAREGIVER TRAINEES

Adapted from Henderson, J. N., Alexander, L. G., & Gutierrez-Mayka, M. (1989). Minority Alzheimer's Caregivers: Removing barriers to community services. Tampa, FL: University of South Florida, Suncoast Gerontology Center.

# Identification of Caregiver Trainees

It is anticipated that some trainers may know African American and rural family caregivers and can encourage them to participate in the workshops they conduct. Others have strong ties with the community and can network through those ties to find caregiver trainees. For example, church leaders can arrange to have notices placed in church bulletins to inform the congregation of the project. Family caregivers will become aware of the workshops to be offered and other church members can be asked to "spread the word". Networking or word-of-mouth advertising may be the single best method for recruiting caregiver trainees.

A sample press release has been prepared to aid in the recruitment of caregivers. Local newspapers are often willing to publicize the activities of projects which provide assistance to the residents of their communities. Be sure to stipulate that the announcement include a reference to funding from the U.S. Administration on Aging. The announcement should also state that the Virginia Center on Aging is conducting the project.

Alternatively, project staff have identified a number of individuals who have agreed to help enlist the participation of caregivers. The list of potential contact or access people identifies those who have agreed to help project trainers recruit the required number of caregivers (that is, ten per team). Most of these resource people are affiliated with community service agencies and organizations that serve Alzheimer's patients and their families.

Establishing a good rapport with the contact persons is very important. The best way to achieve this rapport is by meeting with them personally. This meeting is critically important. The contact person must be assured that you are qualified to be a trainer. The project has identified trainers who: 1) have some knowledge of the training content (Alzheimer's Disease, caregiver issues, etc.); 2) are educators or experienced trainers who can effectively facilitate groups and communicate information to others; OR 3) have strong ties in the community or experience working with community resources. In addition, the best trainers will demonstrate leadership and problem-solving abilities. Good interpersonal skills, patience, and sensitivity to the special needs of African American and/or rural caregivers are also valuable attributes. Finally trainers need to be flexible and able to adjust to the needs of caregivers.

Prior approval from the referring agency head is essential. Contact people must get clearance from their agency or organization before contacting caregivers. The contact person, then, must get permission from the potential caregiver trainees before releasing their names to trainers. Because of their commitment to keeping information about their clients confidential, most agencies and organizations will insist that the initial contact with family caregivers come from them. The agency will call or write to the caregivers to explain the benefits of participating in the project, encourage their involvement, and obtain either oral or written permission allowing the agency to release their names to the trainer.



# Contacting Caregivers and Asking Them to Become Trainees

Once caregivers have agreed to be contacted, trainers should call them to provide more information about the project and obtain their commitment to attend the workshops. Follow each of the steps listed below when making the first contact.

- 1. Review any information that you may have been given by the referring agency concerning the caregivers and their care recipients.
- 2. Introduce yourself clearly and briefly mention how you came to be a trainer (for example, identify your place of employment if it relates to the grant project).
- 3. Explain how you obtained the name of the caregiver, and name the referring agency.
- 4. Describe the goals of the project. In particular explain that the project is:
- a. funded by the U.S. Administration on Aging and sponsored by the Virginia Center on Aging at the Medical College of Virginia/Virginia Commonwealth University;
- b. targeting African American and/or rural family caregivers of elders with Alzheimer's Disease and other dementias;
  - c. designed to help families provide better care for their loved ones;
- d. intended to strengthen caregiving families by providing information about available community resources and services; and
- e. conducting workshops to improve caregivers' knowledge about Alzheimer's Disease and other dementias.
- 5. Discuss how their participation in the workshops would be beneficial. Specifically mention that:
  - a. they are not alone; other caregivers can benefit from their experiences and vice versa;
- b. there are distinct advantages to learning about community resources and services that exist to support caregivers and help them provide better care;
- c. they will learn various tips and techniques which will make them better able to provide care for their loved ones;
- d. the workshops should help them deal with any frustrations or problems they may be experiencing; and
- e. they will learn how to more effectively manage their time and balance their other responsibilities.



Note: As you are explaining the project goals and benefits of the workshops, be sure to allow the caregivers to make comments or ask any questions that may occur to them.

- 6. Explain that they will be asked to attend three (or four, you may want to use the first workshop as an orientation) workshops that will last for about two or three hours. Let them know that the workshops will be organized according to the progression of dementia so that caregivers can get the information they need when they need it. The first workshop will deal with i sues that are important when a patient is first diagnosed or is beginning to first experience symptoms of dementia, that the second workshop will cover issues that arise later on in the illness, and that the third workshop will concern topics that are important towards the end stage. Impress upon them the importance of attending all three workshops, since the information provided will be useful, regardless of their particular situation.
- 7. Be sure to let them know that the workshops are being provided for free and that help is available should they have transportation problems or need someone to sit with their care recipients. It may be important to explain that although the workshops are being provided for free, they will <u>not</u> be accepting charity by attending.
- 8. Be friendly and compliment the caregivers on the efforts they make to provide care for their loved ones. Show concern and understanding.

# Obtaining a Commitment to Attend the Workshops

Once you have explained the project and answered all of the caregivers' questions, it is important to secure a commitment to attend the workshops. It may be premature to ask for an answer with the first contact. If there seems to be any reluctance or hesitance, allow the caregivers to take a few days to think about it before they commit themselves. It may be necessary to meet the caregivers in person to explain the project in more detail and discuss any remaining concerns they may have.

Once a commitment has been obtained, make a second contact and re-emphasize the advantages of participating in the workshops if doubts still remain. Caregivers must understand that they will gain useful and practical information. When a person is overwhelmed with the job of caring for a demended patient, they must believe that participation will be immediately beneficial or they will not be willing to attend.

Finally, find out from the caregivers when it is best for them to attend the workshops. Let them know that you will try to plan the workshops at a time and place that is best for them. Keep careful notes about caregiver availability so that you can conduct your workshops for maximum attendance.



# TIPS FOR SETTING UP A SUCCESSFUL WORKSHOP

- 1. Select a site that is conveniently located for the family caregivers you have recruited. If the group is very small (for example, if several families have been identified to participate) you may have the workshops in one of the participant's home.
- 2. Ask your family caregiver recruits about the best time to hold your workshops and schedule them to meet the needs of the majority.
- 3. If the group of family caregivers attending the workshops is very large, make sure the site can accommodate all of those who will attend.
- 4. Name tags are helpful with large groups of participants. If you purchase self-adhering tags, bring magic markers and ask participants to print the name they wish to be called by in large letters.
- 5. Serving refreshments can encourage participation. Investigate the possibility of having food donated (for example, ask the local Fire Department to furnish Brunswick Stew). This strategy will be especially popular in rural areas.
- 6. If you have recruited your family caregivers through a local church, you may consider scheduling your workshops on Sunday afternoons after church services or immediately following a potluck supper.
- 7. Be sure you have made enough copies of all handouts and evaluation forms for each workshop. Bring pencils!
- 8. Schedule your workshops well in advance and call all of your recruits personally to let them know where and when the workshops will be held. It's a good idea to follow your phone call with a written invitation including clear directions to the workshop site.
- 9. Plan the content of your workshops carefully. Review the material to be presented and make sure you have scheduled enough time to cover all the information you intend to present.



#### November 28, 1994

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#### Dear 7~:

We appreciate your interest in training African American and/or rural family caregivers of persons with dementia. In early fall, trainers will receive two full days of training in preparation for leading their own groups of family caregivers. We will notify you of the dates and sites as soon as details are finalized.

In the meantime, we urge you to begin identifying family caregivers interested in attending the workshops you will offer once your training is complete. It is important that you identify and recruit caregiver participants ahead of time, so that you will be ready to conduct the workshops as soon as you receive your training this Fall. We have enclosed an overview of the project and other information that will be useful in recruiting family caregivers who can benefit from attending your workshops ("How to Recruit Caregiver Trainees," "Suggestions for Outreach in African American Communities," "Suggestions for Outreach in Rural Communities," and "Tips for Setting Up a Successful Workshop.") A list of potential caregiver contacts or access resource persons has been provided. These individuals have agreed to help project trainers recruit the required number of caregivers (that is, a minimum of 10 per training team). The hand-out entitled "How to Recruit Caregiver Trainees," describes how to utilize these resource persons in your efforts to locate and encourage the participation of caregivers. As we expand our list of caregiver contacts, updated copies will be sent to you.

We have enclosed a caregiver recruitment flyer for use in identifying families to participate in the workshops the trainers will conduct. Just fill in your name and phone number as the person to contact and post this flyer in a location where family caregivers may frequent. Consider unconventional locations, such as grocery store bulletin boards, as well as the more traditional placements (doctor's offices, health departments, etc). Let us know if you would like multiple copies of the caregiver recruitment flyer.

A sample news release and a copy of the press release first used to publicize the project (white) have been included. Local newspapers are often willing to publicize the activities of projects which provide assistance to the residents of their communities. It is important that the announcement include a reference to funding from the U.S. Administration on Aging received by the Virginia Center on Aging.

We strongly encourage you to "spread the word" about car project to anyone who would be interested in our activities. Please call us if you think of anyone who would be a qualified



trainer or caregiver contact person. We have also enclosed a trainer flyer to help in recruiting other appropriate trainers for our project. Please post it in a key location where potential trainers may frequent. Let us know if we can send you multiple copies for distribution among your associates who may be (or know of) appropriate trainers to assist in our project.

If you have any questions, comments, or suggestions, please call us at 804-786-1525.

Sincerely,

Constance L. Coogle, Ph.D. Project Co-Director

Ruth Finley, M.S. Project Co-Director

Enclosures:

Project Overview

How to Recruit Caregiver Trainees

Suggestions for Outreach in African American Communities

Suggestions for Outreach in Rural Communities
Tips for Setting Up a Successful Workshop
Potential Caregiver Contacts or Access Resources

Caregiver Recruitment Flyer

Sample News Release & Originial Press Release

Trainer Recruitment Flyer



### Information Meetings on Alzheimer's Disease or Other Dementias for Family Caregivers

February 19, 26 and March 5 10:30 - 12:30

The Meadows Nursing Center 2715 Dogtown Road, Goochland

Do you suspect someone you know may have Alzheimer's Disease?

Are you worried about an older loved one who seems:

- frequently confused
- very moody?
- unable to recall events
- forgetful of important things
- angered at little things
- to have more trouble managing money and household tasks

If your answer to any of these questions is "yes", someone you know may have Alzheimer's Disease or other dementia.

Come and attend FREE community workshops and learn:

- What is Alzheimer's Disease or Dementia?
- How can you help someone with these troubles?
- How can you provide better care?

For more information please contact: Nancy Tatum at 346-0393

or Cathy Churcher at 355-6373 (evenings)

Sponsored by the Virginia Center on Aging and the U.S. Administration on Aging







Sharing in Care

2112 West Laburnem Avenue Suite 206 Richmond, Virginia 23227 (804) 353-9101 FAX: (804) 353-3098

**MEMO** 

December 15, 1993

### WORKSHOPS FOR RURAL OR MINORITY CAREGIVERS

The Greater Richmond and Southside Virginia chapters of the Alzheimer's Association are within the territory of a project being piloted through the Virginia Center on Aging. The project targets rural and/or minority family caregivers of persons with Alzheimer's Disease or related dementia. Family members of those in residential care facilities are not excluded.

Extensively trained community volunteers are forming groups of family members to share education and information during January, February and March. For more information or to discuss providing space for the meetings, please contact Dr. Constance Coogle or Ruth Finley at 804-786-1525.



August 10, 1993

Dear Members of the Clergy,

During recent months we have sent you information about our train-the-trainer project to identify and educate rural and/or African American family members in your area who are providing care for elders with dementia, primarily Alzheimer's Disease. Thus far we have identified a sizeable group of potential trainers whom we will train in the fall (probably late September through early October) and who will in turn share their knowledge about the disease and available resources with caregivers in their communities. We are asking for your assistance in (1) publicizing the availability of training to caregiving families in your congregation, and (2) becoming and/or recruiting a trainer for members of your congregation.

Undoubtedly you are aware of families within your congregation who could benefit from this kind of education. There are two ways in which you can let them know about the training. The first is very non-threatening and was suggested by a minister in your area in response to our previous mailing: just make copies of one of the two enclosed fliers as appropriate (one is targeted to rural churches and the other, to African American churches), cut or slice in two, and use as bulletin inserts. The advantage of this method is that caregivers contact us directly, and we can explain the project more fully either over the phone or through the mail. The main disadvantage in leaving it all up to caregivers is that they be reluctant to take that first step in getting help.

In addition to, or instead of, the bulletin insert, you may prefer another way, that is simply asking family caregivers if they would like to be contacted when training will take place in your area. Your personal contact may provide the encouragement they need to participate. WITH THEIR PERMISSION, please send us their names, addresses and phone numbers on the form provided. Either we ourselves or a trainer in your area will follow-up closer to the time. The advantage of your sending us the names is that they won't fall through the cracks -- we'll follow through with the details. The disadvantage is that some caregivers are still uncomfortable with that role; they feel that it is a sign of weakness to seek out help, or feel guilty that they don't inherently know how to take care of a family member. Consequently they may feel threatened and deny the need for education. The combination of bulletin insert/personal contact is probably the best approach.

Training sessions for caregivers (probably two-four in number, depending on the length of each session), will probably take place from mid-October through December, with the specific dates, time and place to be determined by individual trainers. There is no charge to the caregivers. In fact, a limited amount of financial aid is available to reimburse transportation and adult sitters for those who would not otherwise be able to attend the sessions. Caregivers will



receive handouts and also a list of resources organized to correspond to the progression of the disease.

Several clergy persons and/or their staff or lay persons are planning to be trained and then facilitate training sessions among their congregant caregivers. It's not too late to sign up to be trained and then to become a trainer to your people, but please contact us as soon as possible. Our two-day training of trainers will be repeated two-three times and held in several locations in Central and Southside Virginia to make it as convenient as possible for trainers to attend.

A training manual, formatted in modules that may be adaptable to an already existing social ministry in your church, will be provided for each trainer. In addition trainers will be given a resource directory of community, state and national resources. There is no charge for the training; it is subsidized by a U. S. Administration on Aging training grant. In fact, the only condition for receiving (1) two full days of training; (2) a timely training manual covering not only Alzheimer's Disease and caregiver concerns, but also topics on outreach, how adults learn, etc.; and (3) an extensive resource directory, is to agree to share what you have learned with a group of 10 caregivers who are not necessarily from 10 different families. (If a trainer needs help in reaching the full complement of 10 caregivers, we will assist in sharing names of caregivers who have asked to be notified about training).

Thanks again for your cooperation in helping caregivers to help themselves and their loved ones through education and the identification of helpful resources. We also appreciate your giving strong consideration either to becoming a trainer yourself (if you have not already agreed to) or enlisting a designee from your church to do so. It's well worth the two day's investment of time in exchange for the knowledge as well as the print resources which will be useful for years to come.

Sincerely.

Constance L. Coogle, Ph.D.

Ruth B. Finley, M.S.

enclosures: two versions of bulletin insert

form for listing caregivers

#### **MEMORANDUM**

To: Families in the Metro Richmond Area

From: Constance L. Coogle, Ph.D. and Ruth B. Finley, M.S., Project Co-Directors

Date: November 22, 1993

If you are caring for a relative, neighbor, or close friend because that person is forgetful and/or confused to the point of being unable to carry out daily activities without assistance, then you will probably be interested in the free community workshops we will be offering in many communities now and through the first of the year.

We have trained a large number of volunteers (such as pastors, teachers, community leaders, social workers and nurses) about conditions which can cause extreme forgetfulness and confusion, and whether or not the condition may be reversible. Even if the condition is not reversible (for example, Alzheimer's Disease), these trained volunteers can provide a great deal of information about how friends and family can better take care of their loved ones, and the resources that are available in the community.

Although the community workshops are free and open to the public, pre-registration is necessary and preference will be given to minorities and/or persons living in rural areas. To get more information and to find out where workshops are being held in your community, call the Virginia Center on Aging at 804/786-1525 without delay. The workshops are funded by the U.S. Administration on Aging and will be available for only a short period of time.





#### Medical College of Virginia Virginia Commonwealth University

To: Trainers

From: Constance Coogle and Ruth Finley

Date: September 3, 1993

Hope you had an enjoyable Labor Day, and we thank you again for your willingness to be a trainer for our project, "Training Caregivers of African-American and Rural Elders with Dementia: Progressive Training through Trusted Resources." The purpose of this memo is to give you a status report on the project.

#### Training Manual

This summer we have been diligently working on the training manual which will provide the basis for your training of family caregivers. The revised outline of Part I (Trainer Instruction) is enclosed (yellow). Basic to your training is an understanding of family caregivers—their strengths and weaknesses; their burdens and rewards; and their unique relationships with those for whom they care. These six chapters will increase awareness of the unique aspects of your caregiver group and how you can tailor your approach to maximize effectiveness.

Part II (Caregiver Lesson Plans) is still fluid, but topics are being arranged according to the progression of Alzheimer's Disease (AD). At the present time, there are five modules clustered under early stages, eight under middle stages, and four under late stages. These modules will equip you with up-to-date knowledge about dementia, especially AD. The manual as a whole will provide the foundation of the two day train-the-trainer workshop in which you will participate this fall. (More about that below).

Not surprisingly, the manual has taken longer to create than we anticipated; however it will be worth the wait! Our goal is to produce the best possible product for our funding source (U. S. Administration on Aging) because it will be used not only in Virginia but will also be disseminated nationwide. To this end, the manual will be quite detailed and should thoroughly prepare its users to help the caregivers who are, after all, the focus of our project. The project staff, advisory groups and trainers exist only to support these faithful, tireless individuals, and the training manual provides a tangible means to do so.

#### Train-the-Trainer Workshops

In order for us to plan the train-the-trainer workshops, we have enclosed a Return Feedback Form (salmon), the top half of which will tell us which dates in October and

Virginia Center on Aging ● 520 North 12th Street ● MCV ● Box 229 ● Richmond, Virginia 23298-0229 (804) 786-1525 ● VOICE TDD (804) 786-0956 ● FAX (804) 371-7905



#### And in Conclusion....

As always, we encourage you to "spread the word" about the project. Although our emphasis at this time is on caregiver recruitment, it's not too late to recruit potential trainers and/or access people (i.e., strategic individuals who are aware of both our training project and caregivers who should be informed about the opportunity to participate).

Thanks again for your commitment to training, and don't hesitate to call us if you have specific concerns, questions, needs, etc. We are looking forward to seeing you at the train-the-trainer workshops before too much longer!

#### Enclosures:

Revised Outline of Training Manual (Part I) - yellow Return Feedback Form & Pre-addressed Envelope - salmon Suggested Reading List - pink Magazine Articles (3) - white List of Resource Directories - green



### RETURN FEEDBACK FORM FOR TRAINERS

| Your name  |
|--|
| Mailing Address  |
| Daytime Phone Number   |
| So that we can better schedule regional training dates, please list the dates when you would <u>NOT</u> be able to attend regional training during the months of October and November. Please give us only those dates you will <u>NOT</u> be available. |
| OCTOBER:   |
|  |
| <u> </u>   |
| NOVEMBER:  |
|  |
|  |
|  |
| How many caregivers have you contacted who have agreed to attend your workshops?   |
| Number of minority caregivers? Number of non-minority caregivers?  |
| Total number of caregivers?  |
| Do you anticipate that you will need assistance in locating caregivers in your area?   |
| <ul> <li>[ ] No, I have at least 10 or more caregivers in my training group</li> <li>[ ] Maybe, but I still have more caregivers to contact or confirm</li> <li>[ ] Yes, I know of no more caregivers to contact</li> </ul>                              |
| Do you have 20 or more caregivers in your group and wish to "share" them with a smaller group in your area? [ ] Yes [ ] No   |
| Do not hesitate to call either Ruth Finley or Constance Coogle at the Virginia Center on Aging (804) 786-1525 if you have questions or concerns.   |
| Please return this form in the pre-addressed envelope provided to:   |

Caregiver Project Virginia Center on Aging MCV Box 229 Richmond, VA 23298-0229

Thank you for your continuing interest and cooperation.





To:

Trainers in Southside Virginia

From:

Constance L. Coogle and Ruth B. Finley

Date:

January 31, 1994

Please find enclosed a form for you to indicate when and where you have scheduled your caregiver workshops. We need this information so that we can refer caregivers who contact us directly about attending the sessions. We are trying to match caregivers with trainers who are holding sessions in their communities. Please complete the enclosed scheduling form and return as soon as possible. A return address label is enclosed, or you may FAX us at (804) 371-7905. We may know caregivers who want to attend your workshops! Alternatively you can call either of us at the Virginia Center on Aging (804/786-1525).

If you have already held ANY of your sessions and have not returned the evaluation forms please use the postage paid envelopes (provided during training) to do so as soon as possible. It will help us immensely if trainers return the paperwork for EACH workshop they hold (along with the evaluation coversheet) as soon as they conduct EACH session.

Please call us if we can assist you in planning or conducting your workshops. Remember, each trainer is expected to engage a minimum of five caregivers a piece, and we may be able to assist you in that effort. Thank you again for your commitment to assisting family caregivers of elders with dementia.

Enclosures:

Scheduling Feedback Form

Return Address Label

trsched.mem



### Scheduling Feedback Form

| Please chec    | k one of the follo             | owing option                      | s:                           |                             |
|----------------|--------------------------------|-----------------------------------|------------------------------|-----------------------------|
| 1.             | I have scheduled               | the following                     | workshops to                 | o meet:                     |
| Workshop 1:    | Date                           | Time                              | Place                        | (Address, City/County)      |
|                | _                              | <b></b>                           | D1                           |                             |
| Workshop 2     | : Date                         | Time                              | Place                        | (Address, City/County)      |
| Workshop 3     | : Date                         | Time                              | Place                        | (Address, City/County)      |
|                |                                |                                   |                              |                             |
| Workshop 4     | : Date                         | Time                              | Place                        | (Address, City/County)      |
| 2.<br>3.<br>4. | I have already workshops and r | conducted so eturned evaluated so | ome/all (circlation forms fo | le whichever applies) of my |
|                | NG WITH                        |                                   |                              |                             |



To:

Trainers of Caregivers in Central and Southside Virginia

From:

Constance L. Coogle and Ruth B. Finley

Date:

March 4, 1994

Please find enclosed two sets of reading lists to distribute to those who attend your workshops. One list is targetted at Alzheimer's family caregivers in particular, and the other list includes more general readings for those caring for elderly family members. Both lists will be helpful to those who care for a loved one with Alzheimer's Disease or other dementias. If you need more copies than we have enclosed, please make duplicate copies and save the receipts for reimbursement. Alternatively, we will be happy to mail additional copies to you.

Some of you did not return the Scheduling Feedback Forms included in the memorandum of January 31. We have been trying to telephone those who did not respond to make sure that we know when your workshops are scheduled, and to offer any assistance you may need. If we have been unable to reach you, please call us at (804) 786-1525, or complete the enclosed form and mail it back to us at your earliest convenience. You may also FAX us at (804) 371-7905. We need this information so that we can refer caregivers who contact us directly about attending the sessions! We are also trying to attend some of the workshops ourselves. It is so gratifying to see how our efforts are actually helping families in the community.

We would also like to remind you that workshop evaluation forms should be returned after each workshop you conduct. If you have already held ANY of your sessions and have not returned the evaluation forms please use the postage paid envelopes (provided during training) to do so as soon as possible. It will help us immensely if trainers return the paperwork for EACH workshop they hold (along with the evaluation coversheet) as soon as they conduct EACH session.

Please call us if we can assist you in planning or conducting your workshops. Remember, each trainer is expected to engage a minimum of five caregivers a piece, and we may be able to assist you in that effort. Thank you again for your commitment to assisting family caregivers of elders with dementia.

**Enclosures:** 

Two sets of Reading Lists for Caregivers

Scheduling Feedback Form Return Address Label

trread.mem



### Scheduling Feedback Form

| Workshop 1: | Date   | Time   | Place  |  |
|-------------|--|--|--|--|
| •           |  |  |  | (Address, City/County)   |
| Workshop 2: | Date   | Time   | Place  | (Address, City/County)   |
|             |  |  |  | (Address, City/County)   |
| Workshop 3: | Date   | Time   | Place  | (Address, City/County)   |
|             |  |  |  | (Address, City/County)   |
| Workshop 4: | Date   | Time   | Place  |  |
|             |  |  |  | (Address, City/County)   |
| 2. I hav    |  | luled my work  | shops yet but  | will let you know as soon as   |
| 3. I i      | ve.<br>nave already                                      | conducted so   | ome/all (circ  | will let you know as soon as le whichever applies) of moreach session.   |
| 3. I i wo   | ve.  nave already  rkshops and  nave already             | conducted so<br>returned evalua  | ome/all (circ<br>ation forms forms forme/all (circ                   | le whichever applies) of more ach session.  le whichever applies) of more applies of more appl |
| 3. I i wo   | ve.  nave already rkshops and  nave already rkshops, and | conducted so<br>returned evaluated so<br>conducted so<br>am returning of | ome/all (circ<br>ation forms forms forme/all (circ<br>evaluation for | le whichever applies) of or each session.  |

trread.mem



### Scheduling Feedback Form

| Please check | k one of the follo              | owing option  | is:            |   |
|--------------|---------------------------------|---------------|----------------|---|
| 1.           | I have scheduled                | the following | g workshops to | o meet:                                     |
| Workshop 1:  | Date                            | Time          | Place          |   |
| -            |                                 |               |                | (Address, City/County)                      |
| Workshop 2:  | Date                            | Time          | Place          | _   |
|              |                                 |               |                | (Address, City/County)                      |
| Workshop 3:  | Date                            | Time          | Place          | (Address, City/County)                      |
|              |                                 |               |                | (Address, City/County)                      |
| Workshop 4:  | Date                            | Time          | Place          |   |
|              |                                 |               |                | (Address, City/County)                      |
| 2.           | I have not schedu have.         | ıled my work  | shops yet but  | will let you know as soon as I              |
| 3.           | I have already workshops and re |               | •              | e whichever applies) of my or each session. |
| 4.           | I have already workshops, and   |               |                | e whichever applies) of my ms.              |
|              | RAINER IDENTI                   |               |                |   |
| trread.mem   |                                 |               |                |   |



November 28, 1994

Dr. James Gunnell Vice President for Academic Affairs Saint Paul's College 406 Windsor Ave. Lawrenceville, VA 23868

Dear Dr. Gunnell:

We are planning to hold regional training in your area for our project, entitled "Assisting Caregivers of Minority and Rural Elders with Dementia." As you may remember, our funding source (the U.S. Administration on Aging) has suggested that we work closely with Historically Black Colleges and Universities as host sites for our project meetings. We were quite appreciative of your gracious hospitality when we held the meeting of our Southside Regional Needs and Resources Team meeting at your college on February 4 of this year. We hope that Saint Paul's will be able to help us out again by hosting our regional training event. Your secretary, Ms. Lunette Ellis, asked that we put our request in writing.

We are planning two full days of training on November 4 and 5, from approximately 9:00 a.m. to 5:00 p.m. Although we will not know how many trainees will actually attend until we are closer to our targeted date, there may be as many as 30 participants. Because trainees will need to take notes and fill out forms, we prefer space that is set up for classroom seating with desks or tables for them to write on.

We intend to invite legislators who serve the areas targeted by our project to make a few opening remarks on the first day of training. We would also like to have you and any other appropriate representatives from the College to welcome the trainees. Please let us know who will speak so that we can include this in our agenda. Any pertinent introductory material would also be helpful.

We would greatly appreciate your assistance in arranging for coffee, juice, and muffins or pastries to be provided in the morning on both training days. We would also like to make arrangements for participants to have lunch on campus both days. If this is feasible, let us know what these services will cost per person and we will ask the participants to include payment when they register for the event. We have asked Ms. Ellis, to send us directions to the College and specifics (building, room, parking, etc.) as soon as those details have been resolved.

You have already done a great deal to help us move toward our goal of assisting African American and rural family caregivers. Please accept our sincere gratitude. Your continued support will be instrumental in the success of this undertaking. Please don't hesitate to contact us if we can ever be of any service to you or Saint Paul's College.



Sincerely,

Ruth B. Finley, M.S. Project Co-Director

Constance L. Coogle, Ph.D. Project Co-Director



# Virginia Center on Aging in Cooperation with the Virginia Geriatric Education Center presents

# Assisting Caregivers of African American and Rural Elders with Dementia: Progressive Training Through Trusted Resources

#### Agenda DAY A - November 16 - Woodview Nursing Home

| 9:00 a.m.  | Registration and Refreshments                                      |
|------------|--|
| 9:15 a.m.  | Welcome and Introductions Ruth B. Finley                           |
| 9:45 a.m.  | Pre-Test Evaluation  |
| 10:00 a.m. | Review of Purpose and Rationale for Training Constance L. Coogle   |
| 10:15 a.m. | How to Use the Manual<br>Ruth B. Finley                            |
| 10:30 a.m. | Break  |
| 10:45 a.m. | Overview of Dementia and Alzheimer's Disease Ruth B. Finley        |
| 11:25 a.m. | Caregiver Issues Constance L. Coogle                               |
| 12:00 p.m. | Lunch  |
| 1:15 p.m.  | How Adults Learn<br>Ruth B. Finley                                 |
| 2:15 p.m.  | Break  |
| 2:30 p.m.  | How to Recruit Caregivers/Conduct Workshops<br>Constance L. Coogle |
| 3:15 p.m.  | Evaluation of Training/Post-Test                                   |
| 3:30 p.m.  | Forming Teams  |



### Assisting Caregivers of African American and Rural Elders with Dementia: Progressive Training Through Trusted Resources

#### Agenda DAY B - November 17 - Woodview Nursing Home

| 9:00 a.m.  | Registration and Refreshments  |
|------------|--|
| 9:15 a.m.  | Welcome and Orientation/Pre-Test Evaluation Constance L. Coogle                |
| 9:30 a.m.  | Ethnic Competence for Trainers of African American Caregivers Michael A. Pyles |
| 10:30 a.m. | Break  |
| 10:45 a.m. | Community Resources Panel Presentations - Joan B. Wood, Moderator              |
| 12:15 p.m. | Lunch  |
| 1:30 p.m.  | Special Considerations for Trainers of Rural Caregivers Joan B. Wood           |
| 2:00 p.m.  | Expecting the Unexpected Constance L. Coogle                                   |
| 2:30 p.m.  | Break  |
| 2:45 p.m.  | Presentation of Sample Workshop Ruth B. Finley                                 |
| 3:45 p.m.  | Evaluation of Training/Post-Test   |
| 4:00 p.m.  | Wrap-Up - DAY B  |



#### April 18, 1994

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#### Dear 7~:

First, we would like to thank you again for volunteering your time in support of family caregivers in African American and/or rural communities. We appreciate your good intentions and commitment to the goals of our project. Because you are among the trainers who have not yet scheduled their caregiver workshops, we are urging you to please do so immediately.

The U.S. Administration on Aging provided the grant funds to support our project with the expectation that caregivers would ultimately benefit from the education program we have implemented. We in turn, selected you to be a trainer because we were convinced that you would be able to effectively conduct educational workshops for caregivers in your community. Your attendance at the training sessions we conducted constituted implicit agreement to fulfill your obligation to follow-up and apply the information gained in the conduct of workshops.

In short, just as the federal government provided funding with confidence that we would meet our stated goals, we placed our trust and faith in you. The success of the project now depends on your good will and integrity. We have extended the deadline for the conduct of workshops until the end of May, but time is running short. Please don't let us down! Do whatever is necessary to recruit your caregivers and schedule your workshops.

We want to remind you that part of our grant funds have been set aside to reimburse trainers for out-of-pocket expenses. So please be sure to keep any documentation of direct costs you incur. We still have funds available to be used for respite and transportation should caregivers have a need for that kind of support. If you have had any difficulty recruiting caregivers we urge you to contact the appropriate access resource persons listed at the end of Chapter 6 in your training manual. These individuals have agreed to help our trainers find caregivers to attend their workshops and should be more than happy to assist you. As always, we remain available to offer any assistance you may need. Please call us at (804) 786-1525.

As soon as you have set the dates for your workshops please notify us as soon as possible. We are engaging in some recruitment efforts of our own and may know of caregivers who could attend your sessions. We are also trying to attend some of the workshops ourselves. It is so gratifying to see how our efforts are actually helping families in the community.



We would also like to remind you that workshop evaluation forms should be returned after each workshop you conduct. If you have already held ANY of your sessions and have not returned the evaluation forms please use the postage paid envelopes (provided during training) to do so as soon as possible. It will help us immensely if trainers return the paperwork for EACH workshop they hold (along with the evaluation coversheet) as soon as they conduct EACH session.

Just a reminder about paperwork. Be sure to have the Caregiver survey by all caregivers who attend <u>any</u> of your sessions. Make sure that participants complete both the back and front of the workshop evaluation forms (green sheets) after each workshop (some caregivers failed to notice questions on the back). Also don't forget to collect pre-training (blue) and post-training (yellow) knowledge test responses. We recommend that you give out the blue sheets at the beginning for all modules you will be covering in a given session, and then distribute the yellow sheets at the end along with the evaluation forms (green sheets) at the end of the workshop.

We expect to hear from you shortly about the planned dates and times for your scheduled workshops. We can't over-emphasize the importance of the work you are engaged in or the value of your efforts to the caregivers you will reach. Thank you in advance for your concerted efforts and cooperation.

Sincerely,

Constance L. Coogle, Ph.D Project Co-Director

Ruth B. Finley, M.S. Project Co-Director

trprmemo.mem



#### April 18, 1994

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Sincerely,

Constance L. Coogle, Ph.D Project Co-Director

Ruth B. Finley, M.S. Project Co-Director

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# COMMUNITY INFORMATION WORKSHOPS FOR AFRICAN AMERICAN FAMILIES CARING FOR LOVED ONES WITH ALZHEIMER'S DISEASE OR OTHER DEMENTIAS

Do you know someone who seems:

- \* confused
- \* moody
- \* to have trouble managing finances or other routine tasks
- \* forgetful
- \* easily angered
- \* unable to recall recent events

If your answer to any of these questions is "yes", you should attend the FREE community workshops to be offered in your area this Fall. To learn more about caring for loved ones with any of these symptoms, please contact:

Virginia Center on Aging, Medical College of Virginia Virginia Commonwealth University Box 229 Richmond, Va 23298-0229 (804) 786-1525 (Ask for Dr. Constance Coogle or Ms. Ruth Finley)

Financial aid may be available for transportation and arranging for adult sitters

Sponsored by the Virginia Center on Aging at MCV/VCU and

the U.S. Administration on Aging

# COMMUNITY INFORMATION WORKSHOPS FOR AFRICAN AMERICAN FAMILIES CARING FOR LOVED ONES WITH ALZHEIMER'S DISEASE OR OTHER DEMENTIAS

Do you know someone who seems:

- \* confused
- \* moody
- \* to have trouble managing finances or other routine tasks
- \* forgetful
- \* easily angered
- \* unable to recall recent events

If your answer to any of these questions is "yes", you should attend the FREE community workshops to be offered in your area this Fall. To learn more about caring for loved ones with any of these symptoms, please contact:

Virginia Center on Aging, Medical College of Virginia Virginia Commonwealth University Box 229 Richmond, Va 23298-0229 (804) 786-1525 (Ask for Dr. Constance Coogle or Ms. Ruth Finley)

Financial aid may be available for transportation and arranging for adult sitters

Sponsored by the Virginia Center on Aging at MCV/VCU and

the U.S. Administration on Aging



# Do You Suspect Someone You Know May Have Alzheimer's Disease? Are You Worried About An Older Loved One Who Seems:

- \* frequently confused
- \* exceptionally moody
- \* to have increasingly more trouble managing money and household tasks
- \* forgetful of important things
- \* angered at the "least little thing"
- \* unable to recall recent events

If your answer to any of these questions is "yes", you should attend the FREE community workshops offered to African American families and churches this Fall. To learn more about caring for loved ones with any of these symptoms, please contact your pastor or:

Ruth Finley or Constance Coogle Virginia Center on Aging Virginia Commonwealth University Box 229 Richmond, Va 23298-0229 (804) 786-1525

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#### Reading List for Alzheimer's Family Caregivers

# Constance L. Coogle, Ph.D. & Ruth B. Finley M.S. Virginia Center on Aging

- Alzheimer's Disease Center, University of Southern California (1991). <u>Improving caregiving skills: The stress reduction method</u>. Distributed by the Alzheimer's Disease Education and Referral Center, P.O. Box 8250, Silver Spring, MD, 20907-8250.
- Boyd, J.R., Frieden, S, Higley, K. O., & Spencer, P. E. (1989). How to cope with Alzheimer's disease. St. Louis, MO: Alzheimer's Association, St. Louis Chapter.
- Brown, D. S. (1984). <u>Handle with care: A question of Alzheimer's</u>. New York: Prometheus Books.
- Brunette, M. G., & Fowler, M. L. (1988). The Yankee caregiver . . . If you care for someone with Alzheimer's disease. Gardiner, MN: The Community Resource Center, Alzheimer's Care Center.
- Carroll, D. L. (1989). When your loved one has Alzheimer's: A caregiver's guide. New York: Harper & Row.
- Cohen, D., & Eisdorfer, C. (1986). The loss of self: A family resource for the care of Alzheimer's Disease and related disorders New York: Norton.
- Coughlan, P. B. (1993). Facing Alzheimer's: Family caregivers speak. New York: Ballantine Books.
- Dippel, R. L., & Hutton, J. T. (1988). <u>Caring for the Alzheimer patient</u>. Buffalo, NY: Prometheus Books.
- Family guide for Alzheimer's care in residential settings. Chicago, IL: Alzheimer's Association.
- French, C., Kline, N, & Levine, E. B. (1985). <u>Understanding and caring for the person with Alzheimer's Disease</u>. Atlanta, Alzheimer's Association Atlanta Chapter.
- Gruetzner, H. (1988). <u>Alzheimer's: A caregiver's guide & source book</u>. New York: John Wiley & Sons.



- Guide to home safety for caregivers of persons with Alzheimer's Disease. Available from the Atlanta Area Chapter Alzheimer's Association, 3120 Raymond Drive, Atlanta, GA 30340 or call (404) 451-1300.
- Home safety for the Alzheimer's patient. Distributed by the Alzheimer's Disease Education and Referral Center. P.O. Box 8250, Silver Spring, Maryland, 20907-8250.
- Mace, N. L. & Rabins, P. V. (1981). <u>The thirty-six hour day: A family guide to caring for persons with Alzheimer's Disease</u>. Baltimore, MD: Johns Hopkins Press.
- Noyes, L. E. (1991). Caregiving at a glance. Falls Church, VA: Family Respite Center.
- Oliver, R., & Bock, F. (1987). Coping with Alzheimer's: A caregiver's emotional survival guide. New York: Dodd, Mead & Company
- Powell, L., & Courtice, K. (1983). <u>Alzheimer's Disease: A guide for families</u>. Reading, MA: Addison-Wesley Publishing Company.
- Pynoos J., Cohen E., & Lucas C. (1988). <u>The caring home booklet: Environmental coping strategies for Alzheimer's caregivers.</u> Los Angeles, CA: UCLA/USC Long Term Care National Resource Center.
- Reisberg, B. (1981). A guide to Alzheimer's Disease for families, spouses, and friends. New York: The Free Press, Macmillan.
- Ronch, J. L. (1989). <u>Alzheimer's Disease: A practical guide for families and other caregivers</u>. New York: Continuum.
- Schmall, V. L. & Cleland, M. <u>Helping memory-impaired elders--A guide for caregivers</u>. Oregon: Pacific Northwest Extension Publication.
- Tanner, F., & Shaw, S. (1985). <u>Caring: A family guide to managing the Alzheimer's patient at home</u>. New York: The New York City Alzheimer's Resource Center.



### **Reading List for Family Caregivers**

# Constance L. Coogle, Ph.D. & Ruth B. Finley, M.S. Virginia Center on Aging

- American Association of Retired Persons (1992). <u>Planning for incapacity: A self-help guide.</u> Washington, D.C.
- Crichton, J. (1987). Age care sourcebook: A resource guide for the aging and their families. New York: Simon and Schuster.
- Edinberg, M. (1987). Talking with your aging parent. Boston: Shambhala.
- Foyder, J. E. (1987). Family caregivers guide. Cincinnati, OH: Futuro.
- Halpern, J. (1987). Helping your aging parent: A practical guide for adult children. New York: McGraw-Hill.
- Hooyman, N., & Lustbader, W. (1988). <u>Taking care of your aging family members: A practical guide</u>. New York: The Free Press.
- Horne, J. (1985). <u>Caregiving: Helping an aging loved one</u>. Glenview, IL: Scott Foresman and Company.
- Jarvik, L., & Small, G. (1988). <u>Parentcare: A common sense guide for adult children.</u>
  New York: Crown.
- Kenny, J., & Spicer, S. (1984). <u>Caring for your aging parent: A practical guide</u> to the challenges, the choices. Cincinnati, OH: St. Anthony Messenger Press.
- Levin, N. J. (1987). How to care for your parents. Washington, DC: Storm King Press.
- Manning, D. (1983). When love gets tough, The nursing home decision. Hereford, TX: In-Sight Books, Inc.
- National Association of Insurance Commissioners. (1993). A shopper's guide to long-term care insurance. Kansas City, MO.
- Rob, C., & Reynolds, J. (1991). <u>The caregivers guide: Helping elderly relatives cope with health and safety problems</u>. Boston, MA: Houghton Mifflin.



- Silverstone, B., & Hyman, H. K. (1982). You and your aging parent: The modern family's guide to emotional, physical, and financial problems. New York: Pantheon.
- Tomb, D. A. (1984). Growing old: A handbook for you and your aging parents. New York: Penguin, Inc.



#### April 18, 1994

1~

2~

37~

4?~

5~

#### Dear 7~:

First, we would like to thank you again for volunteering your time in support of family caregivers in African American and/or rural communities. We appreciate your good intentions and commitment to the goals of our project. Because you are among the trainers who have not yet scheduled their caregiver workshops, we are urging you to please do so immediately.

The U.S. Administration on Aging provided the grant funds to support our project with the expectation that caregivers would ultimately benefit from the education program we have implemented. We in turn, selected you to be a trainer because we were convinced that you would be able to effectively conduct educational workshops for caregivers in your community. Your attendance at the training sessions we conducted constituted implicit agreement to fulfill your obligation to follow-up and apply the information gained in the conduct of workshops.

In short, just as the federal government provided funding with confidence that we would meet our stated goals, we placed our trust and faith in you. The success of the project now depends on your good will and integrity. We have extended the deadline for the conduct of workshops until the end of May, but time is running short. Please don't let us down! Do whatever is necessary to recruit your caregivers and schedule your workshops.

We want to remind you that part of our grant funds have been set aside to reimburse trainers for out-of-pocket expenses. So please be sure to keep any documentation of direct costs you incur. We still have funds available to be used for respite and transportation should caregivers have a need for that kind of support. If you have had any difficulty recruiting caregivers we urge you to contact the appropriate access resource persons listed at the end of Chapter 6 in your training manual. These individuals have agreed to help our trainers find caregivers to attend their workshops and should be more than happy to assist you. As always, we remain available to offer any assistance you may need. Please call us at (804) 786-1525.

As soon as you have set the dates for your workshops please notify us as soon as possible. We are engaging in some recruitment efforts of our own and may know of caregivers who could attend your sessions. We are also trying to attend some of the workshops ourselves. It is so gratifying to see how our efforts are actually helping families in the community.



We would also like to remind you that workshop evaluation forms should be returned after each workshop you conduct. If you have already held ANY of your sessions and have not returned the evaluation forms please use the postage paid envelopes (provided during training) to do so as soon as possible. It will help us immensely if trainers return the paperwork for EACH workshop they hold (along with the evaluation coversheet) as soon as they conduct EACH session.

Just a reminder about paperwork. Be sure to have the Caregiver survey by all caregivers who attend <u>any</u> of your sessions. Make sure that participants complete both the back and front of the workshop evaluation forms (green sheets) after each workshop (some caregivers failed to notice questions on the back). Also don't forget to collect pre-training (blue) and post-training (yellow) knowledge test responses. We recommend that you give out the blue sheets at the beginning for all modules you will be covering in a given session, and then distribute the yellow sheets at the end along with the evaluation forms (green sheets) at the end of the workshop.

We expect to hear from you shortly about the planned dates and times for your scheduled workshops. We can't over-emphasize the importance of the work you are engaged in or the value of your efforts to the caregivers you will reach. Thank you in advance for your concerted efforts and cooperation.

Sincerely,

Constance L. Coogle, Ph.D Project Co-Director

Ruth B. Finley, M.S. Project Co-Director

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#### Project Directors' Evaluation of Selected Training Sessions

| Dutc  | e: Coogle |         |            | Finley |       |              |               |  |
|---|-----------|---------|------------|--------|-------|--------------|---------------|--|
| Trainers:   |           |         |            |        |       |              |               |  |
| Place: Session # (circle) 1 2 3   |           |         | Time:until |        |       |              |               |  |
|   |           |         | 4          | 5      | 6     |              |               |  |
| List modules presented &  | circle if | a requi | ired mod   | ule:   |       |              |               |  |
| PROGRAMMATIC AS Facilites/environment Welcoming/introductory  | remarks   |         | Outsta     | anding |       | Satisfactory | Needs Work    |  |
| Administration of Caregiver Survey Administration of Pre-post Tests Administration of Session Evaluations |           | tions   |            |        | •     |              |               |  |
| Pre-post ?'s covered in mini-lecture Level of knowledge Evidence of preparation Closure                   |           |         |            |        | •     |              |               |  |
| INTERPERSONAL AS<br>Leadership ability<br>Respect for caregivers  | PECTS     |         |            |        |       |              |               |  |
| Rapport with caregivers<br>Problem-solving ability  |           |         |            |        | ,     |              |               |  |
| TEACHING OPTIONS  |           |         | 37         | ,      | .,    |              |               |  |
| Refreshments? Video or other A-V's? Experiential exercises? Hand-outs?                                    |           |         | Yes        |        | No.,  |              | emments       |  |
| How many caregivers we  | ere prese | nt?     | Of         | these, | how 1 | many Africa  | ın-Americans? |  |
| What were the best featu  | res of th | e sessi | on?        |        |       |              |               |  |
|   |           | -       | -          |        |       |              |               |  |

What aspects of the session could be improved?



## **APPENDIX II**

Level 1: Revised Pre-Training and Post-Training Knowledge Tests

Training Session Evaluation Form and Code Sheet

Level 2: Revised Pre-Workshop and Post-Workshop Knowledge Tests

Workshop Evaluation Form

Workshop Cover Sheet



# EVALUATION QUESTIONNAIRE PRE-TEST FOR DAY A TRAINING

| Trainer | Identification | Number | <br> | <br> |  |
|---------|----------------|--------|------|------|--|
|         |                |        |      |      |  |

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. Among individuals age 85 and older, the incidence of Alzheimer's Disease is almost:
  - a. 10%.
  - b. 35%.
  - c. 75%.
  - d. 50%.
- 2. Dementia is:
  - a. the same as senility,
  - b. a normal part of aging.
  - c. a loss of intellectual ability that interferes with daily functioning.
  - d. all of the above.
- 3. Alzheimer's Disease is:
  - a. an age-related, chronic cognitive dysfunction.
  - b. the most common form of dementia.
  - c. a progressive, degenerative brain disease.
  - d. all of the above.
- 4. The <u>most conclusive</u> method of diagnosing Alzheimer's Disease:
  - a. is accomplished through a CAT scan.
  - b. is based on the results of IQ tests.
  - c. can be made only upon examination of brain tissue at autopsy.
- 5. All of the following may be accompanied by dementia and are related to Alzheimer's Disease, except:
  - a. hardening of the arteries.
  - b. Parkinson's disease.
  - c. depression.
  - d. Huntington's disease.



| υ. | is the primary symptom of Alzheimer's Disease in the early   |
|----|--|
|    | stages.  |
|    | a. Visual and/or auditory hallucinations   |
|    | b. Forgetfulness   |
|    | c. Wandering   |
|    | d. Long term memory loss   |
| 7. | Caregiver burden:  |
|    | a. impairs the caregiver's ability to provide care.  |
|    | b. can increase the probability that a patient will need to be placed in a nursing   |
|    | home prematurely.  |
|    | c. can be decreased by support from the caregiver's family and friends.  |
|    | d. all of the above.   |
| 8. | is the appropriate way to teach children, while  |
|    | is the best way to teach adults.   |
|    | a. Andragogy, pedagogy   |
|    | b. Pedagogy, andragogy   |
|    | c. Telegogy, envirogogy  |
|    | d. Envirogogy, telegogy  |
| 9. | Older adult learners may have difficulty learning because of:  |
|    | a. medications.  |
|    | b. presbyopia.   |
|    | c. presbycusis.  |
|    | d. all of the above.   |
|    | space provided beside each item write the words "True" or "False" to indicate er you think the statement is true or false. |
|    | 10. Support group participation <u>per se</u> does not result in significant decreases in caregiver burden or depression.  |
|    | 11. Support group participation is most beneficial when it is reinforced with appropriate community services.              |



# EVALUATION QUESTIONNAIRE POST-TEST FOR DAY A TRAINING

| Train      | er Identification Number   |            |
|------------|--|------------|
| For export | ach of the items which follow, circle the letter beside the <u>best</u> answer. nd to each item. If you aren't sure, make your best guess. | Be sure to |
| 1.         | Among individuals age 85 and older, the incidence of Alzheimer's almost:   | Disease is |

- a. 10%.
- b. 35%.
- c. 75%.
- d. 50%.

#### 2. Dementia is:

- a. the same as senility.
- b. a normal part of aging.
- c. a loss of intellectual ability that interferes with daily functioning.
- d. all of the above.

#### 3. Alzheimer's Disease is:

- a. an age-related, chronic cognitive dysfunction.
- b. the most common form of dementia.
- c. a progressive, degenerative brain disease.
- d. all of the above.
- 4. The <u>most conclusive</u> method of diagnosing Alzheimer's Disease:
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  - b. is based on the results of IO tests.
  - c. can be made only upon examination of brain tissue at autopsy.
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  - b. Parkinson's disease.
  - c. depression.
  - d. Huntington's disease.



| Ο.     |        | is the primary symptom of Alzheimer's Disease in the early                     |
|--------|--------|--|
|        | stages | 5.   |
|        | a. Vi  | sual and/or auditory hallucinations  |
|        | b. Fo  | orgetfulness   |
|        | c. W   | andering   |
|        | d. Lo  | ong term memory loss   |
| 7.     | _      | giver burden:  |
|        |        | pairs the caregiver's ability to provide care.                                 |
|        |        | n increase the probability that a patient will need to be placed in a nursing  |
|        |        | prematurely.   |
|        |        | n be decreased by support from the caregiver's family and friends.             |
|        | d. all | of the above.  |
| 8.     |        | is the appropriate way to teach children, while                                |
|        |        | is the best way to teach adults.   |
|        | a. Ar  | ndragogy. pedagogy   |
|        |        | dagogy, andragogy  |
|        | c. Te  | legogy, envirogogy   |
|        | d. Er  | ivirogogy, telegogy  |
|        |        |  |
| 9.     |        | adult learners may have difficulty learning because of:                        |
|        | a. me  | edications.  |
|        | •      | esbyopia.  |
|        | -      | esbycusis.   |
|        | d. all | of the above.  |
| In the | space  | provided beside each item write the words "True" or "False" to indicate        |
|        |        | think the statement is true or false.  |
|        |        |  |
|        | 10.    | Support group participation per se does not result in significant decreases in |
|        |        | caregiver burden or depression.  |
|        | 11.    | Support group participation is most beneficial when it is reinforced with      |
|        |        | appropriate community services.  |
|        |        | •  |



# EVALUATION QUESTIONNAIRE PRE-TEST FOR DAY B TRAINING

| Train         | er Identification Number  |
|---------------|---|
| For earespoon | ach of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to not to each item. If you aren't sure, make your best guess.  |
| 1.            | Which of the following is <u>not</u> $\varepsilon$ barrier that affects service utilization among minority elders and their families?  a. actual or perceived racial discrimination  b. a lower incidence of Alzheimer's Disease and related dementias among minority groups.  c. lack of familiarity with services and providers.  d. lack of minority involvement in service planning and needs assessment. |
| 2.            | Which of the following is <u>not</u> a barrier that affects service utilization among rural elders and their families?  a. limited communication about service availability.  b. geographic isolation and transportation difficulties.  c. negative attitudes about receiving outside assistance.  d. extensive social and economic diversity.  |
| 3.            | The need for information and services may be highest among  |
|               | The proportion of the population in <u>nonmetropolitan</u> areas that is elderly is the proportion of the population in <u>metropolitan</u> areas that is elderly.  a. larger than b. smaller than c. the same as   |
|               | Urban caregivers of elders with Alzheimer's Disease are more likely to receive support from than those in rural areas.  a. caregiver support groups  b. ministers  c. friends and neighbors  d. all of the above  |



- 6. Among African American caregivers of relatives with Alzheimer's Disease, the decision to make a nursing home placement is most often due to:
  - a. lack of support from other family members and friends.
  - b. increased conflict with the patient.
  - c. loss of faith.
  - d. all of the above.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

| <br>7.  | The rural elderly account for the majority of community mental health patients.                                      |
|---------|--|
| <br>3.  | The values of rural elders are "post figurative," that is passed down from older to younger persons.                 |
| <br>9.  | Overall, African Americans who reside in nursing homes are somewhat less functionally impaired than white residents. |
| <br>10. | African American caregivers experience less caregiver burden or stress than white caregivers.                        |



# EVALUATION QUESTIONNAIRE POST-TEST FOR DAY B TRAINING

| rame   | er identification Number  |
|--------|---|
| For ea | ach of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to ad to each item. If you aren't sure, make your best guess.   |
| 1.     | Which of the following is <u>not</u> a barrier that affects service utilization among minority elders and their families?  a. actual or perceived racial discrimination  b. a lower incidence of Alzheimer's disease and related dementias among minority groups.  c. lack of familiarity with services and providers.  d. lack of minority involvement in service planning and needs assessment. |
| 2.     | Which of the following is <u>not</u> a barrier that affects service utilization among rural elders and their families?  a. limited communication about service availability.  b. geographic isolation and transportation difficulties.  c. negative attitudes about receiving outside assistance.  d. extensive social and economic diversity.  |
| 3.     | The need for information and services may be highest among caregivers of elders with Alzheimer's Disease. a. rural, White b. rural, African American c. urban, White d. urban, African American   |
| 4.     | The proportion of the population in <u>nonmetropolitan</u> areas that is elderly is the proportion of the population in <u>metropolitan</u> areas that is elderly.  a. larger than b. smaller than c. the same as   |
| 5.     | Urban caregivers of elders with Alzheimer's Disease are more likely to receive support from than those in rural areas a. caregiver support groups b. ministers c. friends and neighbors d. all of the above   |



- 6. Among African American caregivers of relatives with Alzheimer's Disease, the decision to make a nursing home placement is most often due to:
  - a. lack of support from other family members and friends.
  - b. increased conflict with the patient.
  - c. loss of faith.
  - d. all of the above.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

| 7.  | The rural elderly account for the majority of community mental health patients.                                      |
|-----|--|
| 8.  | The values of rural elders are "post figurative," that is passed down from older to younger persons.                 |
| 9.  | Overall, African Americans who reside in nursing homes are somewhat less functionally impaired than white residents. |
| 10. | African American caregivers experience less caregiver burden or stress than  |



#### VIRGINIA CENTER ON AGING TRAINING EVALUATION - DAY A

| Trainer Identification Number: |  |  |  |  |
|--------------------------------|--|--|--|--|
| I.                             | PARTICIPANT BACKGROUND   |  |  |  |
| Please<br>E, sel               | e fill in your numerical response to the right of each question. For sections A through ect the corresponding number from the attached code sheet. |  |  |  |
| A.                             | Race/Ethnicity   |  |  |  |
| В.                             | Highest Level of Education   |  |  |  |
| C.                             | Discipline   |  |  |  |
| D.                             | Occupation   |  |  |  |
| E.                             | Practice Setting   |  |  |  |
| F.                             | Area of Work or Practice  1. Rural  2. Urban   |  |  |  |
| G.                             | Gender 1. Female 2. Male   |  |  |  |
| H.                             | Approximate percentage of your workshop participants who will be aged 60 or above  |  |  |  |
| I.                             | Approximate percentage of your workshop participants who will be members of ethnic minority groups   |  |  |  |
| J.                             | Approximate percentage of your older workshop participants who will be from rural areas  |  |  |  |
| K.                             | Approximate percentage of your total workshop participants who will be aged 60+ and:  1. Female  2. Male   |  |  |  |



| Circ | le the a  | appropriate number with 1 representing "not at all" and 5 representing "to a great extent."  |
|------|-----------|--|
|      |           | <u>LOW</u> <u>HIGH</u>   |
| A.   | To w      | What extent have your expectations been met?  Quality of program material (audio-visuals and handouts)  1 2 3 4 5  |
|      | 2.        | Usefulness of this program to you 1 2 3 4 5  |
| B.   | 1.        | To what extent did the program broaden your knowledge base?  1 2 3 4 5   |
|      | 2.        | To what extent did the program help you with problem-solving techniques?  1 2 3 4 5  |
|      | 3.        | To what extent do you foresee that this program will have a direct effect on your practices?  1 2 3 4 5  |
|      | 4.        | To what extent did this program affect your view of your participants' quality of life?  2 3 4 5   |
| C.   | How<br>1. | would you rate the overall effective of this training?  Overall effectiveness of the training content  1 2 3 4 5   |
|      | 2.        | Overall effectiveness of the trainers/presenters 1 2 3 4 5   |
| D.   | l.        | What were the most helpful aspects of this training?   |
|      |           |  |
|      | 2.        | What were the <u>least</u> helpful aspects of this training?   |
| E.   | 1.        | Were there relevant topics not covered in this training (please specify)? [ ] yes [ ] no   |
|      | 2         | Please identify those topics which were not covered from those listed on the attached code sheet (II-E Most Vital Topics) and list the corresponding code numbers below. |
|      |           |  |



#### VIRGINIA CENTER ON AGING TRAINING EVALUATION - DAY B

| Trainer Identification Number: |  |  |  |  |
|--------------------------------|--|--|--|--|
| I.                             | PARTICIPANT BACKGROUND   |  |  |  |
| Please<br>E, sel               | e fill in your numerical response to the right of each question. For sections A through ect the corresponding number from the attached code sheet. |  |  |  |
| A.                             | Race/Ethnicity   |  |  |  |
| В.                             | Highest Level of Education   |  |  |  |
| C.                             | Discipline   |  |  |  |
| D.                             | Occupation   |  |  |  |
| E.                             | Practice Setting   |  |  |  |
| F.                             | Area of Work or Practice  1. Rural  2. Urban   |  |  |  |
| G.                             | Gender 1. Female 2. Male   |  |  |  |
| Н.                             | Approximate percentage of your workshop participants who will be aged 60 or above  |  |  |  |
| ī.                             | Approximate percentage of your workshop participants who will be members of ethnic minority groups   |  |  |  |
| J.                             | A. proximate percentage of your older workshop participants who will be from rural areas   |  |  |  |
| K.                             | Approximate percentage of your total workshop participants who will be aged 60+ and:  1. Female  2. Male   |  |  |  |



| Circle | the a  | appropriate number with 1 representing "no  | at all" ano                   | 5 representing "to a great extent."                   |
|--------|--------|---|-------------------------------|---|
|        |        | LOW   |                               | <u>HIGH</u>   |
| Α.     | To w   | what extent have your expectations been met?  Quality of program material (audio-visuals a  1 2 3 4           | nd handouts)                  | 5   |
|        | 2.     | Usefulness of this program to you 1 2 3 4   |                               | 5   |
| B.     | Ι.     | To what extent did the program broaden you 1 2 3 4  | r knowledge                   | base?   |
|        | 2.     | To what extent did the program help you wit 1 2 3 4   | h problem-so                  | olving techniques?                                    |
|        | 3.     | To what extent do you foresee that this prog. 1 2 3 4   | ram will have                 | e a direct effect on your practices?                  |
|        | 4.     | To what extent did this program affect your 1 2 3 4   | view of your                  | participants' quality of life?                        |
| C.     | How 1. | ov would you rate the overall effective of this traised Overall effectiveness of the training content 1 2 3 4 | ning?                         | 5   |
|        | 2.     | Overall effectiveness of the trainers/presenter 1 2 3 4   | S                             | 5   |
| D.     | 1.     | What were the most helpful aspects of this tr   | aining?                       |   |
|        |        |   |                               |   |
|        | 2.     | What were the <u>least</u> helpful aspects of this tra  | aining?                       |   |
|        |        |   |                               |   |
| E.     | 1.     | Were there relevant topics not covered in this [ ] yes [ ] no   | s training (ple               | ease specify)?  |
|        | 2.     | Please identify those topics which were not co<br>(II-E Most Vital Topics) and list the correspond            | vered from the noting code in | hose listed on the attached code sheet numbers below. |
|        |        |   | <u> </u>                      |   |



#### **CODE SHEET**

| <u>I-A.</u> | Race/E | Ethnicity .             |             | 224    | M.S.W.                     |             | 327    | Social W   |
|-------------|--------|-------------------------|-------------|--------|----------------------------|-------------|--------|------------|
|             | 100    | African American        |             | 225    | Pharm.D.                   |             | 328    | Speech F   |
|             | 101    | Asian American/Pacific  |             | 226    | Ph.D.                      |             | 329    | Other (sp  |
|             |        | Islander                |             | 227    | R.N.                       |             |        |            |
|             | 102    | Caucasian               |             | 228    | SCI.D.                     |             |        |            |
|             | 103    | Hispanic, any race      |             | 229    | Other (specify)            | <u>I-D.</u> | Occupa |            |
|             | 104    | Native American/Alaskan |             |        |                            |             | 400    | Academi    |
|             |        | Native                  |             |        |                            |             | 401    | Adminis    |
|             | 105    | Other (specify)         | <u>I-C.</u> | Discip |                            |             | 402    | Clinical   |
|             |        |                         |             | 300    | Audiology                  |             | 403    | Clinical   |
|             |        |                         |             | 301    | Counseling                 |             | 404    | Clinical   |
| <u>I-B.</u> |        | st Level of Education   |             | 302    | Dental Hygiene             |             | 405    | Commu      |
|             | 200    | High School             |             | 303    | Dentistry                  |             | 406    | Fellow/l   |
|             | 201    | A.A./A.A.S.             |             | 304    | Dietetics                  |             | 407    | Hospital   |
|             | 202    | B.A.                    |             | 305    | Family Practice            |             | 408    | In-servic  |
|             | 203    | B.S.                    |             | 306    | Geriatric Medicine         |             |        | Educatio   |
|             | 204    | B.S.N.                  |             | 307    | Gerontology                |             | 409    | Instructo  |
|             | 205    | B.S.W.                  |             | 308    | Health Care Administration |             | 410    | Manage     |
|             | 206    | D.D.S.                  |             | 309    | Health Education           |             | 411    | Nurse P    |
|             | 207    | D.M.D.                  |             | 310    | Internal Medicine          |             | 412    | Nursing    |
|             | 208    | D.O.                    |             | 311    | Medicine                   |             | 413    | Private    |
|             | 209    | D.P.A.                  |             | 312    | Nursing                    |             |        | based Pi   |
|             | 210    | D.P.M.                  |             | 313    | Occupational Therapy       |             | 414    | Student    |
|             | 211    | D.S.W.                  |             | 314    | Ophthalmology              |             | 415    | Other (§   |
|             | 212    | Ed.D.                   |             | 315    | Osteopathic Medicine       |             |        |            |
|             | 213    | L.P.N.                  |             | 316    | Pharmacy                   |             | _      |            |
|             | 214    | M.A.                    |             | 317    | Physical Therapy           | <u>I-E.</u> |        | ce Setting |
|             | 215    | M.B.A.                  |             | 318    | Physician Assistant        |             | 500    | Admini:    |
|             | 216    | M.D.                    |             | 319    | Podiatry                   |             |        | Regulat    |
|             | 217    | M.Ed.                   |             | 320    | Psychiatry                 |             |        | Agency     |
|             | 218    | M.P.A.                  |             | 321    | Psychology                 |             | 501    | Adult D    |
|             | 219    | M.P.H.                  |             | 322    | Public Health              |             | 502    | Busines    |
|             | 220    | M.S.                    |             | 323    | Recreational Therapy       |             | 503    | College    |
|             | 221    | M.S. in Gerontology     |             | 324    | Rehabilitation Counseling  |             |        | health F   |
|             | 222    | M.S.N.                  |             | 325    | Rehabilitation Medicine    |             | 504    | Commu      |
|             | 223    | M.S.S.W.                |             | 326    | Respiratory Therapy        |             | 505    | Commu      |
|             |        |                         |             |        |                            |             |        |            |

|       |             | Agency                         | 607 | Cerebrovascular Diseases   | 639 | Menta  |
|-------|-------------|--------------------------------|-----|----------------------------|-----|--------|
|       | 506         | Federal Facility (military     | 608 | Community-based Care       | 640 | Mino   |
|       |             | V.A., U.S.P.H.S.)              | 609 | Comprehensive Geriatric    | 641 | Mobil  |
|       | 507         | Freestanding Clinic,           |     | Assessment                 | 642 | Mode   |
|       |             | Ambulatory Care Center         | C:O | Confusional States         | 643 | Multi  |
|       | 508         | Health Professional,           | 611 | Crime                      | 644 | Nutri  |
|       |             | College/University             | 612 | Death, Dying, Bereavement  | 645 | Oral 1 |
|       | 509         | Home Health Agency             | 613 | Depression                 | 646 | Osteo  |
|       | 510         | Hospital                       | 614 | Developmental Disabilities | 647 | Outpa  |
|       | 511         | Institution for the Physically | 615 | Diabetes                   | 648 | Parki  |
|       |             | or Mentally Disabled           | 616 | Discharge Planning and     | 649 | Patier |
|       | 512         | Local Public Health Unit       |     | Continuity of Care         |     | Coun   |
|       | 513         | Medical Research Institution   | 617 | Elder Abuse                | 650 | Polyp  |
|       | 514         | Mental Health Center           | 618 | Emergency Care             | 651 | Psych  |
|       | 515         | Military Health Facility       | 619 | Falls                      | 652 | Pulm   |
|       | 516         | Nursing Home                   | 620 | Family                     | 653 | Quali  |
|       | 517         | Other Long-term Care           |     | Dynamics/Caregiving        | 654 | Recre  |
|       |             | Facility                       | 621 | Financing Aging Problems   |     | Activ  |
|       | 518         | Patient's/Client's Home        | 622 | Functional Assessment      | 655 | Relig  |
|       | 519         | Practitioner's Office (solo,   | 623 | Geriatric Evaluation Units | 656 | Respi  |
|       |             | partnership or group)          | 624 | Geriatric Rehabilitation   | 657 | Rural  |
|       | 520         | Professional or Allied         | 625 | Geropharmacy               | 658 | Safety |
|       |             | Health Association             | 626 | Health Care                |     | Preve  |
|       | 521         | Temporary Employment           |     | Financing/Reimbursement    | 659 | Self ( |
|       |             | Agency                         |     | Issues                     | 660 | Senso  |
|       | 522         | Retired/Unemployed, Not        | 627 | Health Promotion and       | 661 | Sexus  |
|       |             | Seeking Employment, Not        |     | Fitness                    | 662 | Skin   |
|       |             | Actively Practicing            | 628 | Health Screening           | 663 | Sleep  |
|       | 523         | Other (specify)                | 629 | HIV Infection              | 664 | Staffi |
|       |             | •                              | 630 | Hospice Services           | 665 | Subst  |
|       |             |                                | 631 | Hospital-based Home Care   | 666 | Suici  |
| II-E. | <u>Most</u> | Vital Topics                   | 632 | Hypertension               | 667 | Surge  |
|       | 600         | Adult Day Health Care          | 633 | latrogenesis               | 668 | Trans  |
|       | 601         | Alzheimer's Disease            | 634 | Incontinence               | 669 | Wom    |
|       | 602         | Arthritis                      | 635 | Infection Control          | 670 | Other  |
|       | 603         | Autonomy                       | 636 | Infectious Diseases        | 2.2 |        |
|       | 604         | Cancer                         | 637 | Institutional Long-Term    |     |        |
|       | 605         | Cardiovascular Diseases        |     | Care                       |     |        |
|       | 606         | Case Management                | 638 | Loneliness                 |     |        |
|       |             |                                |     |                            |     |        |



# MODULE 1: OVERVIEW OF DEMENTIA AND ALZHEIMER'S DISEASE PRE-TEST QUESTIONS

| Caregiver Identification Number  |
|--|
| For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.  |
| <ol> <li>Dementia is:         <ul> <li>a. the same as senility.</li> <li>b. a normal part of aging.</li> <li>c. a loss of intellectual ability that interferes with daily functioning.</li> <li>d. all of the above.</li> </ul> </li> </ol>  |
| <ul> <li>2. Alzheimer's Disease is:</li> <li>a. an age-related, chronic cognitive dysfunction.</li> <li>b. the most common form of dementia.</li> <li>c. a progressive, degenerative brain disease.</li> <li>d. all of the above.</li> </ul> |
| In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.   |
| 3. Alzheimer's Disease is diagnosed by excluding other possible causes.  |
| 4. Alzheimer's Disease can last from two to twenty years.  |
| 5. The onset of Alzheimer's Disease is usually very sudden rather than gradual.  |



#### MODULE 1: OVERVIEW OF DEMENTIA AND ALZHEIMER'S DISEASE POST-TEST QUESTIONS

| Car          | egiver Identification Number  |
|--------------|---|
|              | each of the items which follow, circle the letter beside the <u>best</u> answer. Be to respond to each item. If you aren't sure, make your best guess.                                |
| 1.           | Dementia is:  a. the same s senility.  b. a normal part of aging.  c. a loss of intellectual ability that interferes with daily functioning.  d. all of the above.                    |
| 2.           | Alzheimer's Disease is:  a. an age-related, chronic cognitive dysfunction.  b. the most common form of dementia.  c. a progressive, degenerative brain disease.  d. all of the above. |
|              | he space provided beside each item write the words "True" or "False" to cate whether you think the statement is true or false.  |
|              | 3. Alzheimer's Disease is diagnosed by excluding other possible causes.   |
|              | 4. Alzheimer's Disease can last from two to twenty years.   |
| <del>-</del> | 5. The onset of Alzheimer's Disease is usually very sudden rather than gradual.   |



#### MODULE 2: CAREGIVER BURDEN PRE-TEST QUESTIONS

| Caregiver | Identification | Number |      |      |
|-----------|----------------|--------|------|------|
| _         |                |        | <br> | <br> |
|           |                |        |      |      |
|           |                |        |      |      |
|           |                |        |      |      |

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. The effective caregiver fills all of the following roles except:
  - a. manager.
  - b. enabler.
  - c. learner.
  - d. observer.
- 2. The development of a negative and insensitive attitude about the patient is called:
  - a. caregiver burden
  - b. caregiver burnout
  - c. depersonalization
  - d the mea culpa syndrome
- 3. The physical, financial, and emotional stress of caring for a disabled elderly family member is called:
  - a. caregiver burden
  - b. caregiver burnout
  - c. depersonalization
  - d. the mea culpa syndrome



#### MODULE 2: CAREGIVER BURDEN POST-TEST QUESTIONS

| Caregiver | Identification N | Number | <br> |
|-----------|------------------|--------|------|
|           |                  |        |      |

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. The effective caregiver fills all of the following roles except:
  - a. manager.
  - b. enabler.
  - c. learner.
  - d. observer.
- 2. The development of a negative and insensitive attitude about the patient is called:
  - a. caregiver burden
  - b. caregiver burnout
  - c. depersonalization
  - d. the mea culpa syndrome
- 3. The physical, financial, and emotional stress of caring for a disabled elderly family member is called:
  - a. caregiver burden
  - b. caregiver burnout
  - c. depersonalization
  - d. the mea culpa syndrome



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# MODULE 3: COPING WITH STRESS PRE-TEST QUESTIONS

| Careg  | giver Identification Number  |
|--------|--|
| For es | ach of the items which follow, circle the letter beside the <u>best</u> answer. Be to respond to each item. If you aren't sure, make your best guess.  |
| 1.     | Caregivers can get respite or relief from their caregiving responsibilities by:  a. finding adult day care.  b. hiring a homecare aide.  c. having someone else stay with the care recipient for a few hours.  d. retreat to a "hermit spot" or "quiet hideout."  e. all of the above. |
| 2.     | is the invigorating and challenging kind of stress, while distress is the negative kind of stress to be avoided.  a. Eustress b. Mistress c. Unstress d. Envirostress  |
| 3.     | The syndrome occurs when the body reacts to threat and prepares to either confront of escape it.  a. mea culpa b. give or take c. fight or flight d. make or break   |
| 4.     | All of the following are symptoms that indicate stress, except:  a. dry palms and warm hands  b. pounding heart  c. nightmares  d. change in appetite  |
| 5.     | is a stress-relieving technique based on the theory that tense muscles are the body's response to anxiety.  a. Visualization or guided imagery  b. Progressive relaxation  c. Deep abdominal breathing   |



# MODULE 3: COPING WITH STRESS POST-TEST QUESTIONS

| Care | giver Identification Number  |
|------|--|
|      | each of the items which follow, circle the letter beside the <u>best</u> answer. Be to respond to each item. If you aren't sure, make your best guess.   |
| 1.   | Caregivers can get respite or relief from their caregiving responsibilities by:  a. finding adult day care.  b. hiring a homecare aide.  c. having someone else stay with the care recipient for a few hours.  d. retreat to a "hermit spot" or "quiet hideout."  e. all of the above. |
| 2.   | is the invigorating and challenging kind of stress, while distress is the negative kind of stress to be avoided.  a. Eustress b. Mistress c. Unstress d. Envirostress  |
| 3.   | The syndrome occurs when the body reacts to threat and prepares to either confront of escape it.  a. mea culpa b. give or take c. fight or flight d. make or break   |
| 4.   | All of the following are symptoms that indicate stress, except:  a. dry palms and warm hands  b. pounding heart  c. nightmares  d. change in appetite  |
| 5.   | is a stress-relieving technique based on the theory that tense muscles are the body's response to anxiety.  a. Visualization or guided imagery b. Progressive relaxation c. Deep abdominal breathing   |



#### MODULE 5: LEGAL AND FINANCIAL ISSUES PRE-TEST QUESTIONS

| Caregiver Identification Number  | · <del></del> |
|--|---------------|
| For each of the items which follow, circle the letter beside the <u>best</u> answer. sure to respond to each item. If you aren't sure, make your best guess.                                   | Ве            |
| <ol> <li>Examples of advance directives are:</li> <li>a. will</li> <li>b. Health Care Power of Attorney (medical affairs)</li> <li>c. General Power of Attorney (financial affairs)</li> </ol> |               |

- 2. A <u>durable</u> health care power of attorney:
  - a. will still be valid after a person becomes incapacitated.
  - b. must be witnessed by at least one blood relative.
  - c. must be notarized.

d. all of the above.

d. must be drawn up by an attorney.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

\_\_\_\_\_ 3. A durable General Power of Attorney must be notarized but a Health Care Power of Attorney does <u>not</u> have to be.



#### MODULE 5: LEGAL AND FINANCIAL ISSUES POST-TEST QUESTIONS

| Caregiver | Identification | Number_ | <br> | <br> |  |
|-----------|----------------|---------|------|------|--|
|           |                |         |      |      |  |

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. Examples of advance directives are:
  - a. will
  - b. Health Care Power of Attorney (medical affairs)
  - c. General Power of Attorney (financial affairs))
  - d. all of the above.
- 2. A <u>durable</u> health care power of attorney:
  - a. will still be valid after a person becomes incapacitated.
  - b. must be witnessed by at least one blood relative.
  - c. must be notarized.
  - d. must be drawn up by an attorney.

In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.

\_\_\_\_\_ 3. A durable General Power of Attorney must be notarized but a durable Health Care Power of Attorney does <u>not</u> have to be.



# MODULE 7: MANAGING THE DAILY ROUTINE PRE-TEST QUESTIONS

| Care   | giver Identification Number   |
|--------|---|
| For e  | each of the items which follow, circle the letter beside the <u>best</u> answer. Be to respond to each item. If you aren't sure, make your best guess.  |
| 1.     | The task of dressing the person with dementia can best be facilitated by: a. taking over the task if the person is too slow. b. offering several choices of clothing. c. laying out articles of clothing in the order they are to be put on. d. all of the above. |
| 2.     | The calorie requirements of an older person are the calorie requirements of a younger person.  a. the same as b. greater than c. less than  |
| 3.     | body.  a. Apraxia b. Apoxia c. Dispraxia d. Dispoxia  |
| In the | e space provided beside each item write the words "True" or "False" to the whether you think the statement is true or false.  |
|        | 4. Using bath oil or bubble bath is a good idea because it can make the bathing experience more enjoyable.  |
|        | 5. When patient's resist assistance with Activities of Daily Living, it is recommended that caregivers change the daily routine as much as possible.  |
|        | 6. Since grooming activities such as shaving and brushing teeth are not complex, they are easily performed by persons with Alzheimer's Disease or other dementias.  |



## MODULE 7: MANAGING THE DAILY ROUTINE POST-TEST QUESTIONS-

| Care | er Identification Number   |
|------|--|
|      | of the items which follow, circle the letter beside the <u>best</u> answer. Be espond to each item. If you aren't sure, make your best guess.                                |
| 1.   | taking over the task if the person is too slow.  offering several choices of clothing. laying out articles of clothing in the order they are to be put on. all of the above. |
| 2.   | the calorie requirements of an older person are the alorie requirements of a younger person.  the same as greater than less than   |
| 3.   | is a series of mixed messages sent from the brain to the ody.  Apraxia Apoxia Dispraxia Dispoxia   |
|      | pace provided beside each item write the words "True" or "False" to whether you think the statement is true or false.  |
|      | Using bath oil or bubble bath is a good idea because it can make the bathing experience more enjoyable.  |
|      | When patient's resist assistance with Activities of Daily Living, it is recommended that caregivers change the daily routine as much as possible.                            |
|      | Since grooming activities such as shaving and brushing teeth are not complex, they are easily performed by persons with Alzheimer's Disease or other dementias.              |



# MODULE 12: FORMAL SUPPORTS AND RESOURCES PRE-TEST QUESTIONS

| Careg | Caregiver Identification Number             |  |  |  |
|-------|---|--|--|--|
|       |   | the items which follow, circle the letter beside the <u>best</u> answer. Be nd to each item. If you aren't sure, make your best guess.   |  |  |
| 1.    | caregi<br>a. try<br>b. be<br>c. be<br>d. ge | calling to find formal assistance with caregiving responsibilities vers should do all of the following, except: to call in the late afternoon. specific about the service you want. polite, but firm. the name of everyone you talk to. prepared for the intake interview. |  |  |
| 2.    | a. phy<br>b. inp                            | are Part B helps pay for all of the following, except: ysician services. patient hospital care. tpatient mental health services. ammography screening every other year.  |  |  |
| 3.    | a. lar                                      | Area Agencies on Aging typically have budgets and staff which are Area Agencies on Aging in urban areas. ger than taller than same size as   |  |  |
|       |   | provided beside each item write the words "True" or "False" to ther you think the statement is true or false.  |  |  |
|       | _ 4.  | The Virginia Long Term Care Council supports the development of community-based resources to avoid the inappropriate institutionalization of impaired elders.  |  |  |
|       | _ 5.  | Your local Alzheimer's Disease chapter does not provide services to patients until they are in the middle or late stages of the disease.   |  |  |
|       | _ 6.  | If you are eligible for Medicaid because of low income, you will have benefits that are not provided for by Medicare insurance.  |  |  |



#### MODULE 12: FORMAL SUPPORTS AND RESOURCES POST-TEST QUESTIONS

Caregiver Identification Number\_\_\_\_\_

|    |  | the items which follow, circle the letter beside the <u>best</u> answer. Be nd to each item. If you aren't sure, make your best guess.   |
|----|--|--|
| 1. | a. try b. be c. be d. get                              | calling to find formal assistance with caregiving responsibilities vers should do all of the following, except: to call in the late afternoon. specific about the service you want. polite, but firm. the name of everyone you talk to. prepared for the intake interview. |
| 2. | <ul><li>a. phy</li><li>b. inp</li><li>c. out</li></ul> | are Part B helps pay for all of the following, except: ysician services. patient hospital care. epatient mental health services. emmography screening every other year.  |
| 3. | a. larg  | Area Agencies on Aging typically have budgets and staff which are Area Agencies on Aging in urban areas. ger than aller than same size as  |
|    | -  | provided beside each item write the words "True" or "False" to ther you think the statement is true or false.  |
|    | 4.   | The Virginia Long Term Care Council supports the development of community-based resources to avoid the inappropriate institutionalization of impaired elders.  |
| _  | 5.   | Your local Alzheimer's Disease chapter does not provide services to patients until they are in the middle or late stages of the disease.   |
|    | 6.   | If you are eligible for Medicaid because of low income, you will have benefits that are not provided for by Medicare insurance.  |



## MODULE 14: MANAGING RESISTIVE BEHAVIOR PRE-TEST QUESTIONS

| Caregiv               | er Identification Number   |
|-----------------------|--|
|                       | h of the items which follow, circle the letter beside the <u>best</u> answer. Be respond to each item. If you aren't sure, make your best guess.   |
| a<br>b<br>c           | Persons with dementia may resist bathing because they: a. are depressed. b. fear water. c. are embarrassed to be undressed. l. all of the above.   |
| p<br>a<br>b           | ncontinence of bowel and/or bladder is common among Alzheimer's patients during stages of the disease.  the earlier  the middle  the later  l. all   |
| g<br>a<br>b<br>c<br>n | When patients have trouble performing Activities of Daily Living. it's a good idea to:  a. insist that they let you do things for them even if they are capable.  b. give them a detailed list of instructions to follow.  c. observe their attempts to perform the activities and provide cues when needed.  l. all of the above. |
|                       | space provided beside each item write the words "True" or "False" to whether you think the statement is true or false.   |
| 4                     | 4. One way to cope with incontinence is to restrict water intake to three cups of liquid per day.  |
| 5                     | Laying out a wide variety of different foods on the table at mealtime will help with mealtime difficulties.  |



# MODULE 14: MANAGING RESISTIVE BEHAVIOR POST-TEST QUESTIONS

| Caregi           | ver Identification Number  |
|------------------|--|
| For each         | ch of the items which follow, circle the letter beside the best answer. Be respond to each item. If you aren't sure, make your best guess.   |
| ;<br>1           | Persons with dementia may resist bathing because they:  a. are depressed.  b. fear water.  c. are embarrassed to be undressed.  d. all of the above.   |
| ;<br>;<br>;      | incontinence of bowel and/or bladder is common among Alzheimer's patients during stages of the disease.  a. the earlier b. the middle c. the later d. all  |
| a<br>t<br>c<br>r | When patients have trouble performing Activities of Daily Living, it's a good idea to:  i. insist that they let you do things for them even if they are capable,  i. give them a detailed list of instructions to follow.  i. observe their attempts to perform the activities and provide cues when needed.  l. all of the above. |
| In the indicate  | space provided beside each item write the words "True" or "False" to whether you think the statement is true or false.   |
| 4                | One way to cope with incontinence is to restrict water intake to three cups of liquid per day.   |
| 5                | Laying out a wide variety of different foods on the table at mealtime will help with mealtime difficulties.  |



#### MODULE 16: COMMUNICATING WITH THE PATIENT PRE-TEST QUESTIONS

| Caregiver | Identification | lumber |
|-----------|----------------|--------|
|-----------|----------------|--------|

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. Aphasia refers to an inability to:
  - a. express thoughts in language.
  - b. understand the spoken word.
  - c. recognize a word or phrase.
  - d. all of the above.
- 2. A person with dementia loses the ability to understand what you are saying:
  - a. long after they have lost the ability to communicate coherently.
  - b. at the same time they lose the ability to communicate coherently.
  - c. long before they have lost the ability to communicate coherently.



#### MODULE 16: COMMUNICATING WITH THE PATIENT POST-TEST QUESTIONS

| C | aregiver | Identification Number |  |
|---|----------|-----------------------|--|
|   | -        | <del></del>           |  |

For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.

- 1. Aphasia refers to an inability to:
  - a. express thoughts in language.
  - b. understand the spoken word.
  - c. recognize a word or phrase.
  - d. all of the above.
- 2. A person with dementia may exhibit all of the following language problems, except:
  - a. stuttering.
  - b. misnomia.
  - c. aphasia.
  - d. perseveration.



### MODULE 21: 24 HOUR CARE PRE-TEST QUESTIONS

| Caregiver Identification Number   |
|---|
| For each of the items which follow, circle the letter beside the <u>best</u> answer. Be sure to respond to each item. If you aren't sure, make your best guess.   |
| <ol> <li>According to a recent study conducted by the University of California caring for an institutionalized patient with Alzheimer's Disease costs about a. \$25,000 a year.</li> <li>\$50,000 a year.</li> <li>\$75,000 a year.</li> <li>\$100,000 a year.</li> </ol> |
| In the space provided beside each item write the words "True" or "False" to indicate whether you think the statement is true or false.  |
| 2. The family caregiver is usually discouraged from participating in care plan conferences when a nursing home placement is made.   |
| 3. The person with Alzheimer's adjusts better to nursing home   |



# MODULE 21: 24 HOUR CARE POST-TEST QUESTIONS

| Caregiver Id                         | entification Number   |
|--------------------------------------|---|
| For each of sure to respon           | the items which follow, circle the letter beside the <u>best</u> answer. Be and to each item. If you aren't sure, make your best guess.   |
| caring<br>a. \$2<br>b. \$5<br>c. \$7 | rding to a recent study conducted by the University of California, for an institutionalized patient with Alzheimer's Disease costs about: 5,000 a year.  5,000 a year.  5,000 a year.  00,000 a year. |
| In the space indicate whe            | provided beside each item write the words "True" or "False" to<br>ther you think the statement is true or false.  |
| 2.                                   | The family caregiver is usually discouraged from participating in care plan conferences when a nursing home placement is made.  |
| 3.                                   | The person with Alzheimer's adjusts better to nursing home placement if there are no reminders of home.   |



# Workshop Evaluation Questionnaire Workshop Number \_\_\_\_\_

| Caregiver   | identification N                          | Number   |  |  |
|---|---|--|--|--|
| Please take a few minutes to answer the following questionnaire. We want to find out if this workshop was helpful to you and discover ways to make it more beneficial in the future. There are no right or wrong answers and your responses will remain confidential. You will not be identified personally in any way. |   |  |  |  |
| 1. What i   | s your gender?                            | Male   | Female   |  |
| 2. What i   | s your racial bac                         | ekground?  |  |  |
| White   | Black                                     | Other<br>(please spe   | ecify)   |  |
| 3. Where  | do you live?                              | Rural area   | Urban area                                       | Suburban area                          |
| Use the scanswer in t   | ale which follov<br>he blank beside       | vs and place the each question.  1 = Not a 2 = A litt 3 = Some | it all<br>le                                     | esponds with your                      |
| •   |   | 4 = A  lot<br>5 = Extre  |  |  |
| 4.  | Was the mater problems and                | ial covered in the   | is workshop relevan<br>aregiver?                 | t to your particular                   |
| 5.  | Did attending available in organizations) | the communit   | make you more aw<br>y (that is, servi            | are of help that is<br>ce agencies and |
| 6.  | available in th                           | g this workshop<br>ne community (<br>Area Agency o             | are you more likely for example, your on Aging)? | to use help that is local Alzheimer's  |
| 7.  | Did attending of how the per              | this workshop preson you care for                              | rovide you with a bear feels?                    | etter understanding                    |
| 8.  |   |  | rovide you with a boson you care for?            | etter understanding                    |



|     |        |   | 1 = Not at all 2 = A little 3 = Somewhat 4 = A lot 5 = Extremely                                  |
|-----|--------|---|---|
|     | _ 9.   |   | workshop provide you with a better understanding elp the person you care for live a happier life? |
|     | _ 10.  |   | s workshop do you feel that you have learned some lp you be a better caregiver?                   |
|     | _ 11.  | In general, how u workshop?             | seful did you find the material presented in this   |
|     | _ 12.  | Overall, how effective material covered | tive do you think the trainer was in communicating ed?  |
| 13. | Did tl | he trainer distribute                   | any handout material for you to keep?   |
|     |        | Yes                                     | No  |
|     | _      | If yes, how useful above)?              | did you find this handout material (use the scale   |
| 14. | Did tl | he trainer show any                     | videos?   |
|     |        | Yes                                     | No  |
|     | _      | If yes, how useful                      | did you find the videos (use the scale above)?  |
| 15. | What   | was the most helpf                      | ul aspect of this workshop?   |
|     |        |   |   |
| 14. | What   | was the <u>least</u> helpfu             | al aspect of this workshop?   |
|     |        |   |   |
|     |        |   |   |



# END

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