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# Teens Teaching Alzheimer's Caregivers to Become Tech- Savvy: The Power of Community and Intergenerational Partnerships

Ann Bruner Duesing  
*University of Virginia*

Marilyn Pace Maxwell  
*Mountain Empire Older Citizens*

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## Case Study

### Teens Teaching Alzheimer's Caregivers to Become Tech-Savvy: The Power of Community and Intergenerational Partnerships

By Ann Bruner Duesing,  
M.L.S., and Marilyn Pace  
Maxwell, M.S.W.

#### Educational Objectives

1. Describe a successful technology project for Alzheimer's caregivers in rural, far southwest Virginia which recruited and trained teenagers to teach computer skills to Alzheimer's caregivers and taught the teenagers about caregiving and the disease.
2. Identify barriers for Alzheimer's caregivers to learning and using technology to assist and support them in their caregiving, and identify successful ways to address these barriers.

3. Demonstrate the positive potential of intergenerational partnerships which bring together teenagers and caregivers in a mutual teacher/student relationship.

4. Examine the impact of the technology project in the daily lives of two Alzheimer's caregivers following their participation in the project.

#### Background

Mountain Empire Older Citizens, Inc. (MEOC) is a private, non-profit, community-based organization serving older citizens and family caregivers in the mountainous, Central Appalachian area of far southwest Virginia. Designated in 1974 as the region's area agency on aging for the counties of Lee, Wise, and Scott and the City of Norton, MEOC has placed major emphasis since its inception on the continuing development of a comprehensive, user-friendly infrastructure of family support services for family caregivers, with a particular focus on supporting persons caring for family members with Alzheimer's disease and related disorders.

MEOC developed its services to support family caregivers in direct response to their expressed wishes and needs; these include in-home, emergency, and overnight respite services; 10 community group respite centers based on the Brookdale Social Day Respite Center model; five caregiver support groups; a Caregiver Resource Lending Library; two adult day health care centers; caregiver educational programming; personal care assistance; homemaker services; care coordination; home-delivered meals; and transportation.

In 2002, MEOC partnered with Dr. Michael A. Creedon, gerontologist and consultant with Carlow International, in a grant project to address the potential of computer technology to assist family caregivers. The project was supported by the Alzheimer's and Related Diseases Research Award Fund (ARDRAF) of the Virginia Center on Aging, Virginia Commonwealth University. This project sought to: 1) research whether or not Alzheimer's caregivers in the MEOC service area would recognize learning to

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use technology as an asset to them; 2) determine barriers to caregiver participation in the area's developing wired community; 3) assess whether or not caregivers thought that it would be helpful to learn to use e-mail, a locally developed chat room, and how to locate reputable Internet health and education sites; and 4) determine if caregivers would be receptive to having high school students as mentors and tutors to teach them how to use a computer.

The results from questionnaires and a focus group indicated a very high acceptance by caregivers of the prospect of having teenagers as their teachers; but respondents stipulated that the teenagers should have some understanding and training in working with older learners for the program to be successful. Further, the caregivers wanted the teens to have some understanding of Alzheimer's disease and the stresses associated with family caregiving. Caregivers wished to learn to use a computer to supplement, not replace, their participation in existing support groups and educational programs. All saw benefits to accessing health information, using e-mail, and participating in a local Alzheimer's caregivers' chat room, as supports for their caregiving responsibilities. They expressed a need for information on the changing stages of Alzheimer's disease and their impact on caregiving responsibilities. Caregivers acknowledged that being able to use a computer would be particularly helpful to them during peak caregiver stress times, such as holidays, inclement winter weather, and when they were ill. Finally, they identified the

following as major barriers to their use of a computer: 1) purchase cost, as they were worried about the financial burden of caregiving and viewed the purchase of a computer as a luxury; 2) ongoing cost of Internet connection fees, given their limited budgets; and 3) lack of previous experience, for they did not know how to use a computer and had no one to teach them.

### **Implementing the Intergenerational Project**

Based on these research results, MEOC and Creedon successfully competed for a second ARDRAF project award, "Developing, Implementing and Evaluating Training Modules to Teach High School Students to Teach Alzheimer's Caregivers to Use the Internet Effectively as a Tool to Assist in Caring for Their Family Members." MEOC staff quickly assembled a partnership of well-trained and knowledgeable professionals from local organizations and institutions who volunteered their services and expertise to assist in the development and implementation of the project. Key partners in this project were: Wise County School Board; University of Virginia Claude Moore Health Sciences Library Outreach at UVA Wise; Regional Adult Education Program; North East Tennessee-Southwest Virginia Chapter of the Alzheimer's Association; Powell Valley High School (PVHS) in Big Stone Gap; and various Alzheimer's caregivers. This partnership constituted a work group whose first task was to develop a training manual for high school students who would be recruited as volunteers to teach

Alzheimer's caregivers computer and Internet usage, as well as for participating family caregivers.

The manual the work group developed, "Tech World---An Information Portal," contained eight modules: 1) Understanding Alzheimer's Disease and the Caregiving Role; 2) Understanding Adult Learners: It's All about Them; 3) What is the Computer?; 4) Internet and WWW Exercises; 5) The Internet Explorer Browser; 6) Finding Reliable Health Information on the Internet; 7) Introduction to Using Electronic Mail; and 8) Guide to Using Health Related Newsgroups and Chat Rooms. The manual also contained the agenda and the materials that were covered and evaluated in each of the five Saturday sessions that were conducted in the library and computer labs at PVHS.

The Wise County School Board donated computers for the caregivers and MEOC installed them. MEOC paid the monthly connectivity fees for a full year of coverage for each. The project successfully recruited 25 caregivers and 25 junior students as participants. Most caregivers needed respite services to be able to participate, while some needed transportation; MEOC met these needs. The caregivers, under the tutelage of the teenagers, completed the five-week course successfully.

### **Case Study #1**

Gary and his wife Betty moved to Big Stone Gap from Detroit when he retired. Betty had grown up in the area and Gary had always promised that he would bring her

back home when he retired, despite knowing no one there. Gary, a quiet, self-sufficient and reserved man, was resolved to care for his wife at home when Betty's condition was finally diagnosed as Alzheimer's disease, shortly after their move to the mountains. He devoted himself to her care and became more and more isolated as her disease progressed. Their children and grandchildren lived far away. Gary was feeling more and more disconnected from his family and friends. When he read about the computer class for AD caregivers in the local newspaper, he enrolled immediately and completed the training. He is now e-mailing his children, playing chess on-line with an old friend, participating in the MEOC on-line support group, reading the Detroit newspaper on-line, and connecting with MEOC's respite services and adult day health care services. "The computer training worked my brain. The student was good to show me what to do and how to use the computer and I had never even used a typewriter before. We have a lot of fun and really are a help to each other on our on-line support group," Gary wrote in an e-mail to MEOC.

### Case Study #2

Laura's mother has lived with her and her family the past 12 years and is now in the last stages of Alzheimer's disease. Laura is the primary caregiver, as her husband is still working. Their adult son lives in the home and needs special care as well, which Laura provides. She is a very strong person who manages the household and her caregiving responsibilities while still having time to be of support to

others. She is active in her church, a central focus of her life. The congregation is a source of comfort to her and her family. Laura had a very rudimentary knowledge of computers and always wanted to be able to use the computer more fully. Being confined to the home during the day, Laura wished that she had an outlet that would stimulate her brain while allowing her to be ever vigilant to the needs of her bed-ridden mother. Laura laughed that watching daytime television was akin to being subjected to cruel and unusual punishment. She was familiar with MEOC and its services and quickly enrolled in the computer class. As a result of her training in this project, she is currently using the computer for genealogical research, writing that, "The computer training was informative and taught me computer skills that I didn't have. I now do things on the computer that I didn't know how to do before. Working with young people put it on a level that I could understand. I really enjoy getting on-line with our support group to share and help each other"

### Evaluation

The Final Project Evaluation indicated strong positive results among both the caregivers and the high school teenage tutors. It showed that: 1) Caregivers had a great appreciation of the teen tutors and provided a strong affirmation of the ability of teen tutors to create a positive learning experience for Alzheimer's caregivers; 2) Caregivers appreciated their new skills, were most affirmative of the e-mail and chat room learning, and valued most the ability to connect with

others; 3) Caregivers felt less alone and noted that their new ability to connect with others would help them cope better and to communicate with others in similar situations; and 4) Caregivers felt more confident in their learning ability, with a large number responding that they realized a sense of confidence in their general learning abilities or that their learning abilities were re-awakened.

The teenage students may have learned more than they taught. Analyses of the evaluations indicated that: 1) High school tutors reported that they learned about Alzheimer's disease and related dementias; 2) Nearly 100% of the students reported learning about their partner caregiver and the attendant stresses of being caregivers; 3) The teen tutors were confident, but not brash, in their computer abilities and felt that their skills were helpful and made a difference in the lives of the caregivers; 4) Not a single caregiver respondent complained that their teen tutor went too fast or was impatient. 5) Teens became more aware of caregivers as people, learning to be patient in teaching, for people learn in different ways, and to appreciate the abilities of others; and 6) High school tutors gained insight into life; many came to see a larger picture than just the project and were able to apply what they had learned to their own lives.

In summary, this unusual inter-generational project capitalized on the strengths and characteristics of participants from both ends of the life course. Each gained from interacting with the other. Both

gained from participating in the project. The older caregivers learned that they are not alone, that they can learn new things, and that they can use technology to reach out and connect with others. The teenage tutors gained understanding of Alzheimer's disease, respect for caregivers, and patience, and recognized that they could be valued and effective teachers.

MEOC replicated this project successfully in early 2007 with funding from the Brookdale Foundation Group. Evaluation results confirm the various findings of the previous project.

The results have been presented at: The Brookdale National Group Respite Conference, Denver, Colorado; State Conference on Campus/Community Partnership, Blacksburg; International Rural Network Conference, Abingdon; Carnegie Institute Rural Initiative, United Kingdom; Annual Conference of the Virginia Coalition for the Prevention of Elder Abuse, Virginia Beach; The Mid-Atlantic Chapter Medical Library Association Annual Meeting, Charlottesville; and The Generations United International Conference, Washington, D.C.

### **Conclusion**

This project has demonstrated the hitherto under-realized potential of intergenerational partnerships for improving the capacities of Alzheimer's caregivers. This project established partnerships between high school students and older caregivers that proved to be mutually beneficial. The students learned about the lives of older

adults, the diversity and resilience of age, the strains of chronic caregiving, and the characteristics of Alzheimer's disease. They also learned about themselves and their ability to improve the lives of others. The caregivers learned new skills that enabled them to use the computer to overcome isolation, connect to other caregivers and caregiving resources, and help themselves to continue to grow. They also gained an appreciation of high school students as friends across the generations.

This project has the potential to be replicated in any locale in the nation. The needs and the resources are there. The curriculum developed, "Tech World-An Information Portal," will be available for dissemination in late 2007 and will include, as well, a "How To" manual to provide step-by-step instructions for establishing the program. The project established that teenagers, properly trained, make effective teachers on the use of technology for older learners, specifically Alzheimer's caregivers, and that caregivers may feel comfortable with and enthusiastic about being taught by teenagers. Since the conclusion of the training sessions, caregivers in our projects have continued to communicate via e-mail with other caregivers, to participate in an on-line support group, and to pursue their individual interests on the computer. Moreover, some have maintained a connection with their teenage partners.

### **Study Questions**

1. If you wished to implement a project like this, who would be the most effective partners to work with in your area in order to make it successful? What could each bring to the table to address barriers to participation by Alzheimer's caregivers in your locale?
2. Identify the ways that being able to use a computer could combat the isolation and loneliness of some Alzheimer's caregivers.
3. What are the benefits to students participating in this project?

### **About the Authors**



Ann Bruner Duesing, MLS, is the Outreach Librarian for the University of Virginia Claude Moore Health Sciences Library and is based at the University of Virginia's College at Wise. She has held this position since it was established in 1995. Ann provides health information services and resources access for the southwest Virginia region.



Marilyn Pace Maxwell, MSW, is the Executive Director of Mountain Empire Older Citizens, Inc, the Area Agency on Aging, Public Transit Organization and Children's Advocacy Center serving far southwest Virginia. She has served in that position since MEOC's inception in 1974. She is a member of Virginia's Commission on Alzheimer's Disease and Related Disorders.