



## *Joint Commission on Health Care*

### **SUMMARY OF PUBLIC COMMENTS: Replicating JMU's Caregivers Community Network Study**

#### **Organizations/Individuals Submitting Comments**

Six comments were received regarding the study on replicating JMU's Caregivers Community Network which was presented to the Joint Commission on Health Care in May. Comments were submitted by:

- Lynne Seward on behalf of the Virginia Adult Day Health Services Association (VADHSA)
- Courtney Tierney on behalf of the Virginia Association of Area Agencies on Aging (VAAAA)
- Bernice Stipic
- Ken Lane
- Ginny Joseph
- Barbara Meadows

#### **Public Comments on Policy Options**

Four caregivers (**Bernice Stipic, Ken Lane, Ginny Joseph, and Barbara Meadows**) discussed the benefits they and their loved ones received from JMU's Caregivers Community Network Program. Courtney Tierney on behalf of the **Virginia Association of Area Agencies on Aging** commented in support of "expanding the availability of regular respite in the community with best practices from around the country guiding that work." Lynne Seward on behalf of the **Virginia Adult Day Health Services Association** specifically supported Option 4 to include a staff study in 2012 regarding the availability of respite care services.

**Option 1:** Take no action.

**Option 2:** Introduce a budget amendment (language and funding) for the Virginia Department for the Aging to provide grant funding of \$370,900 GFs for two demonstration projects to replicate JMU's Caregivers Community Network at other colleges or universities in the Commonwealth.

**Option 3:** Introduce a budget amendment (language and funding) for the Virginia Department for the Aging to provide grant funding of \$509,400 GFs for three demonstration projects to replicate JMU's Caregivers Community Network at other colleges or universities in the Commonwealth.

**Option 4:** Include on the JCHC 2012 work plan, a staff study of the availability of respite services for caregivers in the Commonwealth (Option added by JCHC members).

#### ***Comment Excerpts***

**Lynne Seward of the Virginia Adult Day Health Services Association (VADHSA) commented in support of Option 4:**

"As adult day health care professionals and providers of respite care, we can validate the importance of regularly scheduled respite in decreasing depression and stress among caregivers and its ability to increase coping skills and wellness for both the caregiver and family member needing care...Dozens

of studies over the past 20 years have identified respite as the most desired and needed service by caregivers themselves, and by service professionals who work with family caregivers...Although a full range of sources of respite is not available in all Virginia communities, even in areas where it is readily available, resources are underutilized and also underfunded. Many caregivers are reluctant to ask for help and paying for that help is an additional barrier for many...What we need is to restore and fund more adequately the respite services that are available such as the respite grants and the home and community based waivers. Although, the community network is an innovative idea and concept, the cost appears prohibitive and research indicates that caregivers need consistent respite at least two full days to get the full benefit.”

**Courtney Tierney of the Virginia Association of Area Agencies on Aging** commented without supporting a specific option by stating (in part):

“We would ask that the Joint Commission on Health Care recommend expanding the availability of regular respite in the community with best practices from around the country guiding that work. We ask that you seek out these successes and work to ensure that our Virginia families can access them.”

**Bernice Stipic** commented without supporting a specific option by stating (in part):

“I am a full-time caregiver to my husband of 49 years. He has Alzheimer’s and has had it for 9 years now. The students from JMU’s nursing and other medical fields have been an immense help to me. Each semester, I’m assigned two students who come to the house for several hours each week and engage my husband in activities such as puzzles, books, cards, Lincoln Logs, etc. He seems to enjoy their company, and it allows me to run some errands or just take a walk or work in the yard. I truly believe, as a retired nurse myself, that this time benefits the students as well as my husband and myself. Students are able to see how such a patient deals with Alzheimer’s in the home environment, and I feel it provides a different perspective on how they care for future patients of dementia. The student visits certainly help in my being able to take care of my husband at home, rather than a nursing home...I think a similar program in every college that has a nursing program would greatly benefit the student and the communities. I feel so blessed to have such a program in my community.”

**Ken Lane** commented without supporting a specific option by stating (in part):

“I have used students from the Caregivers Community Network for the last 3 years...For me, as my wife’s caregiver, this program has given me a break from the rigors of caregiving...This program, in association to other programs, has enabled me to keep her home for an additional year.”

**Ginny Joseph** commented without supporting a specific option by stating (in part):

“My husband, 61 year old Alzheimer’s patient,...has always been a mentor to young college students and the CCN program has been a great help to him...He loves the students’ visits for company...Bill currently does not need full time help, but this program gives him a piece of sunshine in the days they visit. He asks me everyday who is coming today. I would encourage you to continue funding this program because it is beneficial to the students who are going to be working with dementia patients. As a caregiver, I like knowing that Bill is having something to look forward to even though it is only twice a week.”

**Barbara Meadows** commented without supporting a specific option by stating:

“I would like to express my benefits from the CCN. I moved my father from Maryland after his wife passed away, he was lonely during the day because I have to work. The students who were sent really played a role in giving him something to look forward to each week. They would have different activities, take him for walks and most of all put a smile on an 81 year olds face. My dad was always happy with the students who were sent. This is a wonderful program for the elderly who cannot get out themselves.”