

PCAD Project



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Dear Agency,

Thank you for considering participating in this national study funded by the National Institute of Disability and Rehabilitation Research and administrated through the University of Maine's Center on Aging. Matthew Janicki, Ph.D., is the Principal Investigator, and Kate De Haven is the Project Coordinator.

Background

Given that the numbers of persons with intellectual disabilities affected by dementia will only increase (currently estimated at 9,000 in the US, but expected to double in the next 15 years -- Janicki & Dalton, 2000), there is a need to explore support models that can help families and other carers cope with early and mid-stage dementia of adults with intellectual disabilities. Continued community integration can only result from applying models of supports that enable people with Down syndrome and other intellectual disabilities to remain with their families or live supported in "dementia-capable" community care settings.

To help construct interventions or support programs relevant to community environments, it is necessary to better understand both the nature of the changes in support and caring provided in at-home situations and the progression of agency capabilities at handling dementia-related care in community care settings. Essential also is to understand how the caregiving situation changes as early to mid-stage Alzheimer's disease progresses and how it affects the family dynamics and continued commitment to care at-home. Adults with Down syndrome can experience a precipitous decline in functions and care demands can take a substantial emotional toll on family and staff resources.

Many families providing at home care have been characterized as long-term "adaptive copers" and may not experience the same types of stress as do carers of spouses with late-onset dementia. However, even among "adaptive copers" the changing burden may cause disruptions in the commitment and ability of parents to continue as the primary carers. We know that carers of adults with dementia are particularly susceptible for stress and an aging of their immune system and run a higher risk of getting sick themselves.

It is probable that "adaptive copers" may be doubly affected as they continue to provide care, but are now faced with a son or daughter exhibiting face-paced diminishing abilities. Thus, our study targets families of adults with Down syndrome for two reasons.

The first is to better understand caregiving at home and the impact of caregiving when dementia is present, and the second, to identify interventions that may help aging informal carers cope with dementia-related care for adults with DS. Given that the onset of Alzheimer's related dementia occurs about 15-20 years earlier in this group than the general population this group of families is well suited for this type of investigation.

What is required?

Your agency is asked to select and allocate one staff person who will organize and run a support group and/or provide information to 'learning-at-home' carers by way of sharing print information. The support groups should consist of a small number (4-12) of carers who are caring at home for an adult with Down syndrome or other intellectual disability who is age 30 or older. The staff member will run the support group on a weekly basis for four (4) weeks or on a fortnightly basis for eight (8) weeks. Preference should be given for group membership to carers who have, at home, a son or daughter (or other relative) with ID who is experiencing aging-related decline or is showing the early signs of (or has been diagnosed with) Alzheimer's disease. The topic areas covered in the group session will be: 1) General Aging, 2) Nutrition and Physical Conditions, 3) Adult Dementia and Decline in Health, 4) General Information and Services, and we will provide the outline materials for each topic. Normally, the groups will run for 90 minutes in duration, beginning with a topic speaker or a showing of a DVD (provided by the Investigator) that lasts for 30 minutes. A general group discussion will take up the remaining 60 minutes.

As part of the study, your agency will be asked to administer a small number of research questionnaires to the group and to the 'learning-at-home' participants. Because this is a research study, the protocols and process have been approved by the ethics review board at the University of Maine. As part of the requirement of the board, the key staff person at your agency will be asked to take the University of Maine's internet training program for researchers. This will be an opportunity to learn the history and ethics of research with human subjects and to be added to a list of those qualified to lead the local part of a research study. The training is a short, one hour Internet-based tutorial and instructions for its completion will be provided by the University of Maine and the PCAD research team. The study will run through the end of March, 2008.

What is offered in return?

A stipend of \$500 per group will be provided to the agency to offset costs of potential speakers and to provide amenities at the group meetings. In addition, a nominal amount of money will be available for childcare and/or travel for support group members. A stipend of \$100 will be provided to agencies willing to provide information to the 'learning-at-home' participants. Informational packets and any handouts used in the support groups will be provided by the investigator.

If you would like to participate in our study, please contact Kate De Haven at 1-207-581-3586 or at: kate.dehaven@umit.maine.edu. Information about dementia and our project is available at www.uic.edu/orgs/rrtcamlr/dementia.